

McPartland Lab

NEWSLETTER

Happy New Year! I hope you are all keeping safe and warm during these chilly winter days. Our research group enjoyed time with family and friends during Yale's December break and are back in the lab ready to do exciting and important clinical science in 2022.

Our research studies are progressing well, and I am grateful for all of you who have come in to participate. I have really enjoyed the opportunity to meet many of you in person during your visits. It is fun to talk with you all about your experiences, and I am delighted to hear about your enthusiasm for participating in research. We will be launching new studies in the coming months (some described in this newsletter), and we are appreciative of your partnership in carrying out this work. Thank you!

I've included a photo of our team's winter gathering. Believe it or not, there was no plan to wear gaudy holiday attire; I guess we have similar (questionable) taste in clothes!



Best wishes,
Jamie McPartland

Practical Parenting Advice

Teaching Functionally Equivalent Replacement Behaviors

By Christine Cukar-Capizzi, PsyD, BCBA

In attempts to communicate, regulate uncomfortable emotions, escape demands, or gain access to preferred objects and activities, children with autism spectrum disorder may engage in challenging behaviors (e.g., tantrums, property destruction, aggression, self-injury, stereotypy, etc.). This often serves as a source of frustration for parents, who try to help manage and decrease the frequency of these behaviors. One helpful strategy parents can use to help decrease challenging behaviors is to teach a functionally equivalent replacement behavior (FERB). By first understanding the *function* of an undesired behavior, one can then devise and teach a FERB that serves the same purpose as the challenging behavior (e.g., obtain, maintain, avoid, or escape a situation) in a more socially appropriate and safe manner.

Importantly, a FERB may not necessarily be the long-term desired behavior you're hoping your child will use, but may provide a short term, alternative behavior that allows your child to meet their needs in a more efficient and socially appropriate way. For example, if your child has a huge tantrum every time you serve broccoli with their dinner, you can teach them to say something like, "No, thank you!" instead. In this scenario, saying "No, thank you!" serves the same function as throwing a tantrum (escape or avoidance of a demand), but does so in a more socially appropriate way. Furthermore, your child will learn that using a FERB (saying "No thank you!") is more efficient and effective than engaging in a tantrum. Once your child is appropriately able to indicate their refusal for a non-preferred item or activity, you can then work towards further shaping this behavior towards your ultimate desired outcome (e.g., offering a choice of vegetables, working towards eating one small piece of broccoli along with a serving of a

preferred vegetable, eating a serving of broccoli every other week, etc.). Ultimately, when the FERB is reinforced rather than the challenging behavior, the challenging behavior will be rendered ineffective. Here are some examples of FERBs for some common behavior problems:

Challenging Behaviors	Functionally Equivalent Replacement Behaviors
- pushing children on the playground to get attention	- asking children to play on the swings or go down the slide
- getting too close when approaching and greeting peers	- approaching and greeting peers while maintaining socially appropriate personal space
- changing the channel on the TV while family members are watching a show	- asking family members for permission to change the channel
- interrupting parents when they are talking on the phone or having a conversation with another family member to ask a question	- saying "Excuse me" and waiting for acknowledgement prior to asking a question
- engaging in verbal refusals/tantrums when working on a difficult homework assignment	- asking for a break or for help with the assignment
- engaging in self-stimulatory behavior during unstructured time	- engaging in a preferred leisure activity (e.g., puzzles, Legos, reading, etc.)



Take some time to think about what challenging behaviors you may want to target for reduction in your home, teaching one FERB at a time. Before long, everyone will be eating broccoli with their dinner!

Sibling's Corner

Your Friends, Autism, and You by Julie Wolf, PhD

If you have a brother or sister with autism, you might not be sure what to tell your friends about them. You might be afraid to talk about your sibling because you're not sure what your friends will think. Maybe you are worried that they will make fun of you or your sibling. Sometimes you might feel embarrassed by your brother or sister's autistic behaviors and want to avoid being seen with them around your friends. Or maybe you just want your time with your friends to be a break from your time with your sibling. You might feel bad about feeling this way, but don't worry – all these feelings are perfectly normal.

Do you want to talk to your friends about autism but aren't sure where to start? Here are some suggestions:

- Tell your friends about autism: It means your brother or sister's brain has developed differently, so that it's harder for them to communicate and know how to get along with other people. They may also have some behaviors that seem unfamiliar. You can describe to your friends what kinds of things your sibling does – whether it's talking about a certain

topic a lot, flapping their hands, saying certain phrases over and over again, etc.

- Talk about your sibling's strengths! Maybe they are really good at art or math. Maybe they can build a tower out of blocks that can reach above their head. Maybe they don't usually talk at all but recently they said their first word. Or maybe they have an amazing memory for lines from their favorite movie. Whatever it is, talk about it with pride – your friends will be more likely to accept your sibling if they can see how much your sibling means to you.
- Talk to your friends about how common autism is. The latest estimates are that 1 out of every 44 kids has autism. That means that there's a very good chance your friends know someone else who has autism – maybe a cousin or a close family friend. If they do, ask them to tell you about that person! You may find some commonalities, but you will probably also discover how unique each person with autism is.
- Tell your friends what they can do for you. If you want your sibling to feel more included, ask your friends if it's ok for your sibling to join you the next time you go to a movie or play a board game. If you need to vent, ask your friends if they're willing to lend an ear. If you are just in need of a break, let your friends know that you want your time with them to be autism-free for a while.

By talking to your friends about autism, you'll not only get your own needs met, but you'll also help your friends to be more understanding and accepting of differences!



In last winter's newsletter, we mentioned that our lab had received funding from the National Institutes of Health (NIH) to continue the Autism Biomarkers Consortium for Clinical Trials (ABC-CT) study for another five years. This project is the largest study of the brain in autism in this country and has included more than 400 families across sites at Yale, Duke University, UCLA, the University of Washington, and Boston Children's Hospital. Based on the first phase of the ABC-CT, two of our measures were accepted into the Food and Drug Administration's (FDA) Biomarker Qualification Program. Here is a link to a recent news story from NIH highlighting this progress:

<https://www.nimh.nih.gov/news/research-highlights/2020/testing-and-refining-biomarkers-to-support-intervention-research-for-children-with-autism.shtml>. We have continued to work with the FDA to gather information to determine how they might be used to improve clinical care in autism. During the past two years, families from the initial research study have come back to the labs for a follow-up visit two to five years after their original participation. This will help us understand how stable these measures are as children mature into adolescents.

With this follow-up study approaching completion, we are ready to begin the next part of the ABC-CT study – a *confirmation study* that will help us ensure the findings from the original study are true in a new group of children. **We need your help!** If you have or know children between the ages of 6 and 11 with or without ASD, please consider partnering with us in this research. Our goals are ambitious, but, with the

support of our local autism community, we are confident we can meet our important scientific objectives. We will compensate you for your time and provide you with a clinical evaluation and report, and we hope we will have fun together during your visits to our lab! If you are interested in learning more or participating in the study, please contact us at 203-785-6108 or email our team at abc-ct@yale.edu.

Thank you!

Spotlight on – PATH



PATH CT is a statewide grassroots family organization providing services for over 35 years to families in Connecticut. We are dedicated to connecting and empowering families, children, and youth living with disabilities or special healthcare needs through support, education, and advocacy.

PATH has the support of the nation's four largest networks for families of children with disabilities and special healthcare needs. We are the Alliance Member of Parent to Parent (P2P) USA, an Affiliate Organization of Family Voices, and State Chapters for Sibling Leadership Network, and National YASA (Youth As Self Advocates). This support gives us the ability to provide much more support to families that contact us.

The heart of PATH is our **Parent Support Program**, a one-to-one matching service through which we provide parent support with a trained

veteran parent who has “been there” and understands what a newly diagnosed family is going through. This training also features an introduction to Charting the LifeCourse, an approach designed to help individuals with various abilities to improve their lives by increasing their personal self-determination and enhancing independence throughout their lifespan.

As the **CT Family to Family Health Information Center**, we are designed to inform, educate, train, and support parents and professionals in issues related to health and healthcare services. We assist with special education advocacy, cultural competency training, autism training, and genetic resource services. We connect our families with local, state, and national resources/information, and help them navigate the healthcare system.

CT KASA (Kids As Self Advocates) is our program created by youth for youth that empowers young people about leadership, advocacy, healthcare, education, and transition to adulthood. CT KASA is open to youth and young adults ages 13 to 26, who are living with a disability or chronic health condition. They have worked on projects such as: testifying on the Police Accountability Task Force Committee; conducted Facebook Live trainings on How to Access Telehealth, Healthcare Transition, and created animated videos and accompanying social stories. Dear HeathPro is a project that was developed to educate providers on how to communicate with youth. Lastly, they created two manuals. Train the Trainer was created to help those organizations who would like to develop a youth program and the Mentor’s Program to train adult self-advocates to mentor KASA’s young adults as they exit the program.

CT Sibling Network supports siblings of individuals with disabilities in the State of Connecticut by providing the information, tools,

and community resources to enrich their lives and the lives of their siblings.

For more information on PATH CT, please email info@pathct.org, call 203-234-9554 or 800-399-PATH (CT Only).

Q&A with a Lab Member



Introduce Yourself!

Hello! I’m Cassie, and I’m a Sara Sparrow pre-doctoral fellow in the McPartland Lab. When I’m not in the lab, you can find me enjoying all the great hiking New England has to offer!

Why did you join the lab?

I have grown up alongside a younger brother with profound autism and have been asking questions about the brain for as long as I can remember. As a sibling, my experience with research began on the participant side. This made me interested in conducting my own research, which I began as an undergraduate studying neuroscience and communication disorders. The McPartland lab afforded me the opportunity to continue working with families affected by autism in all its forms, begin clinical work, and continue growing as a neuroscientist. It has been such a rewarding experience working with our families and on a talented, supportive, and collaborative team!

Is there anything coming up in the McPartland Lab that you're especially excited about?

I continue to be excited by one of our current EEG studies which focuses on a subpopulation of the autism spectrum that has not been well-represented in the research literature – those with significant intellectual disability. It's been incredibly humbling to be part of an effort to include families like my own in neuroscience research. McPartland Lab families, thank you so much for all you have done and continue to do to help us better understand the brain!

Contact Us!

For more information about our research please contact Erin MacDonnell at autism@yale.edu or (203) 737-3439.

[Click here](#) if you would like us to contact you about participating in our studies or scan the QR code.



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Yale Autism Program



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Article Summaries

Our lab has been working on an exciting new project! We have added an “Article Summaries” section to our website where you can find easy-to-understand summaries of some of our recently published scientific papers. We hope that this will allow more people to learn about our work and allow families to see what we do with the data we collect during their visits with us. You can find these summaries by visiting our website at <https://medicine.yale.edu/lab/mcpartland/>, clicking on the Publications tab, and then selecting Article Summaries. Below is an example.

“The N170 event-related potential reflects delayed neural response to faces when visual attention is directed to the eyes in youths with ASD”

Link: <https://pubmed.ncbi.nlm.nih.gov/33749161/>

This study looked at how children's and adolescents' brains responded when looking at different parts of a face. Typically developing children and adolescents processed eyes faster than other parts of the face, whereas this pattern was not seen in ASD. Children and adolescents with ASD processed eyes more slowly than typically developing children. These findings suggest that observed inefficiencies in face processing in ASD are not simply reflective of failure to attend to the eyes.

The McPartland Lab stands in solidarity with the Black community, and we pledge to work to actively fight systemic racism. As a lab within an institution of higher learning, we are committed to providing education around issues of diversity of all kinds, standing up against injustices, and ensuring that our work reflects and benefits the diverse community that we serve. We strive to create a space in which all feel welcome and respected, from our employees to our students, to the families who participate in our research.