

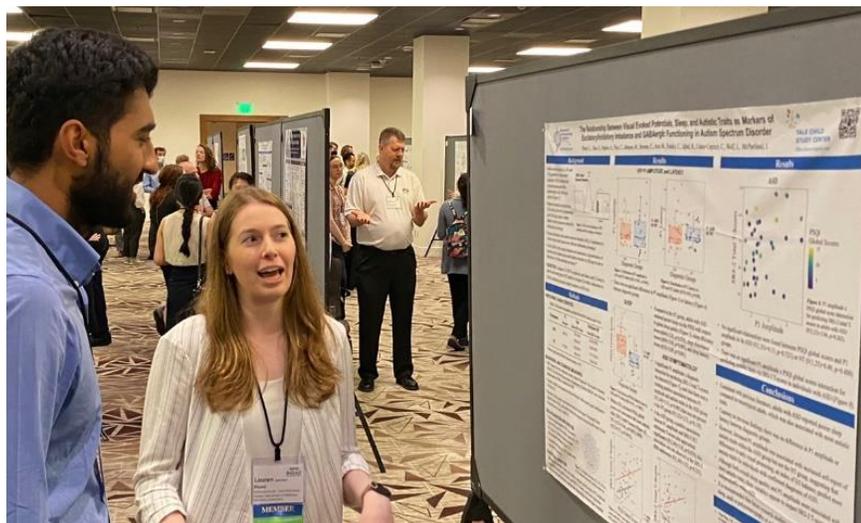
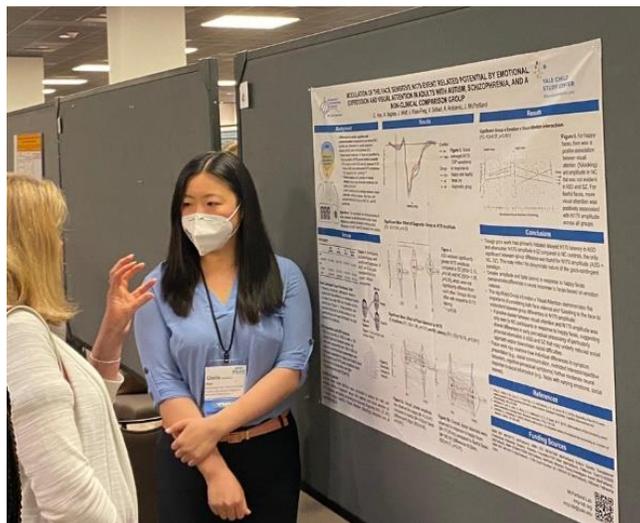
McPartland Lab

NEWSLETTER

Welcome to the Spring/Summer 2022 edition of the McPartland Lab Newsletter. We have benefited from the lengthening daylight hours to be even more productive! The group worked very hard over the winter months to prepare for the International Society of Autism Research (INSAR) Meeting this May. This is an important conference for our research group. It gives us the opportunity to share our work with the research community and to benefit from input and discussion with other scientists. It is also a great time to network with clinicians, scientists, and autistic people. We feel strongly that our best clinical work and research comes from this collaborative community. INSAR also offers our trainees the chance to present their research, often for the first time. For your enjoyment, I've included some images of the future of autism research in action!

We remain so grateful for your partnership in working to maximize the quality of life for all autistic people and their families. These INSAR posters and presentations reflect your hard work as well!

Best wishes,
Jamie McPartland



Sibling's Corner

The Positive Traits of Autism

by Julie Wolf, PhD

Did you know that being a sibling of someone on the autism spectrum can be associated with a lot of positive traits? Here are some traits that are common in siblings of people with autism:

- **Empathy, compassion, and acceptance of people's differences:** Because of your sibling, you understand that not everyone is the same and that we can celebrate people's differences! And because of that, you may not be as quick to judge others who seem different. In fact, siblings are often the ones to stand up for other kids who are being teased or bullied. Being a sib teaches a lot of empathy and compassion towards others.
- **Patience:** Let's face it - sometimes being a sib requires a lot of patience. Your brother or sister may take longer to accomplish things, and you need to be patient. When you talk to your sib, they may not respond to you right away (or at all) and that requires patience. Your sibling may have meltdowns or aggressive behaviors that require a lot of (you guessed it...) patience! You have probably had a lot more practice being patient than other kids your age, and that is something that will really benefit you throughout your life.
- **Maturity & responsibility:** Have you found yourself helping out with your sibling? Maybe you're helping them learn to take turns during a game or teaching them a skill like how to jump rope. Or maybe you find yourself helping your

parents around the house. It is common for siblings to help out in these kinds of ways, and as a result, siblings can sometimes be more mature and responsible than other kids their age.

- **Pride and appreciation of others' accomplishments:** As a sibling, you've probably watched your brother or sister work very hard to accomplish a goal that might come naturally to people who don't have autism. As a result, you may feel very proud of your sibling. Siblings often are more appreciative of other people's accomplishments because they are more aware of how hard people sometimes have to work to achieve their goals.
- **Caring for others:** Because of all the above, siblings are natural caretakers. You may find that you are always the one lending a hand to others, offering support to a friend, or caring for people when they are sick or hurt – it just comes naturally to you! In fact, when they grow up, siblings often choose jobs that involve helping others – you will find a lot of siblings who are doctors, nurses, psychologists, social workers, etc.

So, the next time you are feeling frustrated with your sibling, take a deep breath and remember – you might just be a better person because of them!

Understanding Brain Differences in Profound Autism

During the past few years, autism researchers have increasingly discussed a 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 re-conceptualizing 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.

A new research program in our laboratory is focused specifically on this population. We have developed a specialized set of procedures and designed a special lab setup 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.

As we launch this study, we ask for your help. If you have a child between the ages of 6 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.

If you would like to find out more about this exciting new study, contact Bela Ponjevic at (203) 785-6108 or autism@yale.edu.

Guest Column: Driving with Autism

By Andrew Arboe

The ability to drive is often seen in our culture as a milestone for individuals to achieve. It opens pathways to new types of employment and education, new housing opportunities,

socializing opportunities, and many other things that increase the quality of one's life. Being able to drive is a very important skill, and for some it is an exciting milestone to strive for and reach, but for some it's not. Especially for autistic individuals like myself. I didn't get my license until I was 25, a far cry from the 16 or 18 we typically think of. But driving is a bigger part of my life now than it is for most, neurodivergent or neurotypical. I obtained my license in 2018 and have now driven for over three years. During that time, I've vastly expanded my work involvement on the topic of driving and creating a company called Driving with Autism. I've given dozens of talks and consultations on learning to drive as an autistic person, and I've traveled quite far to do so at times. Driving is core to who I am, so it surprises many that I didn't learn to drive until I was 25. In this piece, I am going to attempt to convey why I did not learn to drive earlier and how that's directly related to the reason why I created Driving with Autism.

Depending on the circumstances and if someone has a disability, learning to drive can be an anxiety fraught experience to the very end, and some never even reach getting their actual license. I have found that as an autistic individual especially, following my own unique path to driving was what made my journey to this milestone successful. This milestone is often ambiguous to autistic individuals, especially when it's just assumed they will or will not reach it, without looking into why they might want or not want to and what they can achieve through hard work, determination, and the right supports. Learning to drive is very personal to me because of my own experience facing challenges and working towards accomplishments while learning to drive at my own pace. Most people start thinking about driving around the age of 16, when it's just becoming legal for them to pursue learning to drive and receiving their license. For myself, it just wasn't something I thought about,

until far later than the age of 16. I felt comfortable enough with buses because they did everything I needed them to for getting to work and attending community college trips. I have found this is true for a lot of autistic people, we don't want things just because they're expected of us, we need a good reason that something is important to our current life. Driving wasn't important to my current life, and I had a lot going on that was important.

I wasn't spending my early adulthood thinking about learning to drive, I spent it learning to address the new needs and expectations of a life post high school. This was very tough. People usually call it 'The Cliff' where students with disabilities and their families rapidly age out of all of their current services within a few years around the age of 21 or 22 with no ability to replace many of them since services for adults are in far less supply. It was a major change and I had to learn a lot about myself to get through it. It specifically took me a while to figure out what I really wanted out of life at that moment, which was to complete my time at Manchester Community College. I chose that over the idea of driving, and I think it was a reasonable choice. It was only when I wanted to advance my work life that buses were not cutting it for me and the need for driving was apparent. It took me finding a good reason to want to drive to feel the drive to do it, and eventually I found a very good reason, that the mentoring jobs I was interested in required driving. So, I decided it was time, I finally felt the motivation, and I got to work making it happen.

At first, I had feelings of shame that I was coming in so late to pursue driving. The ability to drive would have made some previous trips I did with others more doable and might have allowed me to have been at events I had not been able to attend due to lack of transportation. I've realized during my work

though that people choose their licenses at varying ages, and that's a good thing. I concluded that one should never rush the license process and that one should not think about age in terms of what may have been missed out on. There's always stuff to miss out on, regardless of what decisions you make in life, but learning to drive is a difficult process with real safety consequences, and I am very thankful I took my time with it. A piece of advice I often give in consultations is "If someone needs more time, they need more time. It's that simple." It took me a year and a half to complete my driver's practice and to obtain my license. It was not without challenges, and some of them almost kept me from following through. One major challenge was making it work, despite my own anxiety and the lack of resources about driving as an autistic person. There was no Temple Grandin of driving to reference, so I really could feel that I was on my own in ensuring that I pushed myself and worked hard. I had to create my own routine, while considering my limitations. One limitation was that I drove only on the weekends at first because of my work and school schedules at the time. I persevered and kept working to build routinely driving into my life. It was tough to feel 'ready' because I didn't know what that exactly meant for an autistic driver, I was definitely getting more comfortable with it though. Eventually in October 2018, I obtained my license right before my permit expired.

I realized that it was an unintended blessing that things went as they did because my experience became a foundation for my company, Driving with Autism. I originally just aimed to do a presentation about my experience getting my license for a few schools and autism organizations in Connecticut. I ended up giving it a couple of times and then got asked to do more. I never expected for my first workshop with the Connecticut Family Support Network (CTFSN) to go as successfully as it did. And in July 2019, where I also got the attention of a driving school.

A year later I became deeply involved with designing the school's autism driving program. Eventually I wanted to go bigger. I had the idea of doing more national work and I realized how more impactful I could be. I could help people far beyond Connecticut. I left my work at the driving school and turned my focus to developing what is now my proudest creation and addition to the autism advocacy conversation, my company Driving with Autism.

Driving with Autism is a company that offers many services and resources built around helping autistic individuals and their families make smart and informed decisions about learning to drive. I know that a reason to learn to drive can appear at any time, and when it does autistic individuals should have the opportunity to explore it effectively and strive for what they want in life. This is why we work hard to help the individuals we work with every step of the way, from whenever they sign up, to actually receiving their license. The main feature of Driving with Autism is our multi-part webinar series that goes over driver's education prep for autistic individuals. This is one of the best ways we've found to help autistic drivers. In the webinar we cover vital yet often overlooked driving topics like sensory needs, managing driving situations, and financial basics. Things that I wish I would have had as they would have made me feel much more prepared for my learning to drive journey. By attending our seasonal webinar, you also gain access to our resource library, which contains documents to help you jumpstart your journey. Once you complete the series, we will help connect you to local resources and driving schools. That way, you will save money, time, and energy! Especially compared to going to a high-cost program that may not fit your needs. No matter your past experiences from driving, we are here to support you all the way through to obtaining your license!

The path to becoming an autistic driver might be unique, but that doesn't mean it needs to be completely unexpected. I have found that I had some of the exact same barriers as other autistic drivers, and I learned a lot from how they overcame them. Conversations about driving as an autistic individual need to be more commonplace, and we all need to work to make that happen. So as a kid I could have understood that driving was a valuable skill, but still something I can approach on my own time, while also knowing what supports were there for me as an autistic individual. This is the process I work to share and lay out for any autistic individual interested in driving. I believe creating a level of understanding and informed decision making around driving sets them up for success in a way typical driver's education never does. Driving can be so important to anyone's life, and that includes autistic people. I know how important it's been to mine, and it truly didn't matter at what age I received my license.

For more information, please visit <https://autismdriving.com/>

Q&A with a Lab Member



Introduce Yourself!

My name is Cassandra Franke, and I am a first-year Sara S. Sparrow Fellow in the McPartland Lab. I grew up outside of Richmond, Virginia and graduated from the University of Notre Dame in 2021 with majors in Neuroscience and Italian. In

my free time, I enjoy cooking, painting, and playing piano!

Why did you join the lab?

During my time at Notre Dame, I majored in neuroscience and worked at a clinical psychology lab, so joining the McPartland Lab allowed me to explore my interests in both those fields of research more deeply. Now I get to meet and work with so many wonderful children and adults when I run study visits with the other members of our research team, so thank you all for participating in our research and making me excited to come to work every day!

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.

“Brief Report: Preliminary Evidence of the N170 as a Biomarker of Response to Treatment in Autism Spectrum Disorder

Link: <https://pubmed.ncbi.nlm.nih.gov/34267691/>

Individuals with Autism Spectrum Disorder (ASD) often experience difficulties with social communication, such as identifying and understanding faces. Currently, most autism research relies on descriptions provided by clinicians, parents, or caregivers. In this study, we wanted to explore whether Pivotal Response

Treatment (PRT), a commonly used behavioral intervention for autism, would change brain activity in response to faces in children with ASD. We found that brain activity in response to viewing faces changed and became faster for children who had completed 16 weeks of PRT, while it did not change for children who did not receive the intervention.

Contact Us!

For more information about our research please contact **Bela Ponjevic** at autism@yale.edu or (203) 785-6108.

[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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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.