McPartland Lab

NEWSLETTER

Greetings from the McPartland Lab!

The days are growing longer and warmer, and we are looking forward to Spring! This season of renewal feels especially appropriate this year, as we look to begin emerging from some of the constraints of the pandemic. We have worked hard to develop strategies to continue our clinical and research activities safely, and we have experienced success. We are grateful to the many families who have collaborated with us during this time. Our continued scientific progress reflects our partnership with families and our shared investment in improving the welfare of those affected by autism. Our entire research and clinical teams are now vaccinated, and we are glad that we can feel even more confident in our ability to work together safely. We are optimistic that we will have the opportunity to see many more of you this spring!

In this edition of our newsletter, we highlight a new research approach designed to include children with severe autism or limited verbal abilities in neuroscience research. As always, we will introduce a member of our team and provide some advice that we hope will be helpful to families. We are glad you are enjoying these newsletters! Be well!

Best wishes,
Jamie McPartland



New Research Study Using Advanced Technology

Neuroscience research is critical for understanding autism. However, for some children, participating in neuroscience research can be difficult because it involves written and spoken instructions that they may not understand. Almost all neuroscience experiments involve verbal instructions that may not be the best way of communicating with some children with autism. For this reason, we know much less about the biology of autism in children who have difficulties using or understanding verbal communication. A goal of our lab is to create opportunities for these individuals to participate in research.

Recently we have developed a computer program that will help people participate in research without needing to understand complex instructions. We call this program PELICAN (Participant Empowering Learning Infrastructure for Characterization and Neuroscience). Instead of using instructions to tell someone to sit still or pay attention, PELICAN tracks whether a child is paying attention or sitting still and rewards them for improvement by playing an engaging movie. We based this approach on the way a teacher or therapist uses positive feedback to shape behavior. But unlike a teacher, PELICAN is tracking attention and movement 1000 times per second! This speed allows us to apply this information to control precise neuroscience experiments.

PELICAN opens the door for children with limited verbal expression or comprehension to participate in a wider range of research than ever before. We are now starting our first study using PELICAN to study some of the same biological markers, or biomarkers, used in the Autism Biomarkers Consortium for Clinical Trials (ABC-CT). These biomarkers help us understand what happens in our brain when we see faces. By using PELICAN to welcome a more diverse group of children into neuroscience research, we gain a better understanding of the brain in autism. This is our first study using PELICAN, and we're excited to share it with you here.

These advancements would not have been possible without the partnership and support of the families in the research process. With this new approach we hope to make new connections as well as see old friends.

If you would like to find out more about this exciting new study, contact Erin MacDonnell at (203) 737-3439 or autism@yale.edu.

Coronavirus & Comp Ed: Ensuring Our Children with Disabilities Are Receiving a FAPE

By Jeffrey L. Forte, Esq. | Forte Law Group LLC |

A & La

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A Special Education Attorney
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Regardless of the area of law, all attorneys must meet with a prospective client in what is commonly referred to as "the initial legal consultation." This critical meeting is the first meeting that is held between you, the potential new client, and the potential attorney. As a practical matter, I use the term "potential" because you are in essence both checking each other out and mutually gathering information and advice that can help with your potential case. The process of the initial legal consultation also helps both the potential client and attorney decide whether or not they legally and ethically want to move forward and work together by establishing an official attorney-client relationship.

Regardless of how formal or informal the initial legal consultation may be, it is critically important that both the potential client and the potential attorney come fully prepared in order to make the best use of your time (and money) together.

Below are my recommendations for parents who have never met with a special education attorney before but are planning to do so. Following my tips will maximize your valued time when meeting with

an experienced special education attorney. These examples are based on my practice but are true for most law firms.

Fill out and return your client questionnaire and documents in a timely manner.

For all potential new clients, I take time to thoroughly prepare for all initial legal consultations reviewing bv client vour questionnaire form and all the documents you send to my office in advance of our first meeting. This helps me to evaluate your potential claims, determine any statute of limitations, and to conduct a preliminary case evaluation of potential claims and remedies for you. Your time with me will be most productive if you fill the questionnaire out fully and send your child's records to my office in a timely manner before the initial legal consultation.

Look through the information on the attorney's website.

The information provided on the Forte Law Group website is intended to answer some of the basic questions parents commonly have when they come in for an initial legal consultation. It should not be construed as legal advice, because it does not account for the technicalities that may come into play for your child's particular situation. It should, however, give you a feel for the basic vocabulary used in the area of special education law and also provide you with a listing of the recent results achieved for the many families I represent throughout Connecticut. Many of my blogs also address child special education issues and provide an understanding of the progression of different types of special education cases from PPT meetings to mediation and due process litigation. The tips and information we provide on our website are free.

Have a written list of questions to which you can refer.

Just as you would do before going to a PPT meeting, you should write down any questions you have so that you do not forget to ask them. I encourage you to write down a list of questions

you have for me, so you can refer to the list during the initial legal consultation. If your loved ones and anyone else you trust have specific questions, write those down in advance as well. Just trust me on this one: you will not be able to concentrate on the wealth of information I provide you with during the initial legal consultation if you are thinking of your next question!

Bring or forward copies of all the documents you have that are relevant to your child's education.

Oftentimes your child's education records that you thought meant nothing to you could mean everything to me best advocating for your child. If you have copies of your child's evaluations, assessments, progress reports, and the like, please bring them in or forward them to us so we can review them during your appointment. Sometimes these records can explain the causes of action and potential claims better than you, the potential client, can!

Be ready to take a few notes.

It can be difficult to remember what you discussed with me days or even weeks later when the situation arises again. My office and I encourage all potential new clients to take a few notes on important discussion topics during the initial legal consultation, so they have something to jog their memory later. Additionally, there may be follow-up information or documents we need you to obtain before we can take the next step, and it is always helpful to have those types of instructions written down.

Adult decisions require adult attendance, so expect your family members to sit in the waiting area during your appointment.

Given that your child's education is a joint and mutual parental decision, it is important that both parents (or the parent with educational decision-making authority if separated or divorced) personally attend the initial legal consultation. For parents that are divorced, please refer to my published law article, <u>Divorce and Special Education</u>: A <u>Primer For Family Law Attorneys and Divorced Parents of a Child with a Disability</u>.

I recommend that you confer with your trusted loved ones before going into the initial consultation so that you are able to get answers to their questions. Due to the current Coronavirus pandemic, most practices also offer virtual video appointments.

The initial legal consultation is more or less about one hour.

Although my office schedules each initial legal consultation for one hour, your actual appointment may technically last more or less than one hour. It depends on the complexity of your situation and how much information you were able to have organized before your initial consultation with me. Either way, you will leave the initial legal consultation with a proposed strategy in mind. Thus, it is to your advantage to come fully prepared (by following the above tips, of course!) to discuss your situation.

How the sausage is made: what actually happens at the attorney-client initial legal consultation.

I will take time to understand your child's situation, develop your legal claim(s), and determine with you what our realistic legal strategy and remedies should be to resolve your child's education claims to the fullest extent available by law. I will patiently and thoroughly take time to answer your questions, separate legal myths from legal facts, and otherwise, ease your worries about the unknown. I provide advice and explanations tailored to your child's situation that stems from my years of experience, education, and specialized training. I promise to guide our clients with straight-talk and compassion. You may not hear what you expected, or what you want to hear, but we won't hide the legal realities of your case from you. Instead, we face the realities of your case head-on. I often ask potential new clients what is the end result that you wish to seek for your child and sometimes seek a solution around the law rather than through the law to achieve the right result without the litigation fight or emotional toll on your family. Practically speaking, we offer both virtual consultations and in-office consultations.

To retain or not retain, that is the question.

Meeting with me for the initial legal consultation does not mean you are required to hire me as your lawyer to represent you. Indeed, hiring an attorney may not be appropriate for your situation. Parents frequently come in for an initial consultation with questions about their child's education and end up not needing to hire a special education lawyer!

The decision is always yours to make at any point in time. However, you should expect an experienced special education attorney to present to you a retainer amount, a retainer agreement, and a proposed legal strategy towards the end of the initial legal consultation.

COVID Through the Eyes of ASD

By Anson Cohen

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This is what my life was like a year ago: I was taking the train into New York City every day for my bookkeeping internship, a job that I loved. I was looking forward to getting a full-time job as a certified bookkeeper, so I could propose to my long-time girlfriend. In addition to that, I was also singing in a great choir, and was looking forward to its 35th Anniversary Celebration. Then the pandemic happened, and everything changed for me.

It wasn't easy growing up with autism. It was hard to make friends. I tried to fit in and be popular but wasn't successful at that. School was extremely difficult for me, both socially and academically. I had anxiety about the future, and about getting a job where I would fit in with the world.

Then I met my girlfriend in college. She loves me and accepts me for who I am, like I do her. We have been seeing each other on weekends for the past 8 years. She is the love of my life.

After college I decided on bookkeeping as my career. I completed all of my coursework and had finally found the right place to complete my internship. Working there made me feel valued and liked. I was a member of a team and was

making an important contribution to a non-profit organization.

Being a member of a really good choir also gave me a feeling of being part of a community, and also allowed me to use my musical talent. Singing gave me a lot of pleasure as well as giving me lots of positive attention. Everything was going well, and I saw the path towards my future.

In March of last year, everything changed for me. I lost my job overnight due to staff cutbacks, I was unable to see my girlfriend for months, and I lost my social life and my opportunity to sing with my choir when the world was shut down due to COVID. I couldn't even sing at karaoke or in synagogue. My gym closed down, so I didn't have a place to exercise. My anxiety came back, too.

I have been out of work for a year now and am anxious about how to complete my internship. I don't know when I can get a job so I can propose to my girlfriend. I also have no idea when I will be able to sing again. I haven't been able to visit my only living grandparent because of COVID. Sometimes, I feel depressed and sleep too much. Time goes by so slowly.

I still know that I am one of the lucky ones. I have a family that loves me and supports me. Both of my parents still have jobs. I started seeing my girlfriend again, although there are lots of activities that I still can't do with her.

I have a caseworker at BRS that is looking for an internship for me. I am back to seeing my therapist, who is helping me with my anxiety. The gym has opened up, and I am able to exercise again. I know that many people don't have as much support as I have.

I hope the world goes back to normal at some point soon. I miss life without the restrictions of a pandemic.

Practical Parenting Advice

Parents Deserve a Pat on the Back By Christine Cukar-Capizzi, PsyD, BCBA



As the calendar turns from winter to spring, we are reminded that one year has passed since the COVID-19 pandemic brought about uncertainty, unpredictability, and significant changes to our daily activities and routines. This year has been especially trying for many parents of children with autism, who often rely on structure and predictability in their daily lives. Children with autism are often taught new routines and behaviors through a gradual process that involves careful teaching, shaping, and reinforcement over a period of time, a luxury that was not granted by the abrupt COVID-19 outbreak.

Nevertheless, parents put forth tremendous effort to support their children with autism in learning new routines, such as wearing face masks, using hand sanitizer regularly, engaging in social distancing and maintaining personal space, and switching back and forth between distance and inperson learning. Without a doubt, parents demonstrated courage and willingness to make herculean adjustments in the most trying of circumstances. Parents, we hope you take some time to reflect on the remarkable effort put forth to support your children in adapting to the events of this past year, and also celebrate your accomplishments, big and small alike! Perhaps the experience of this past year will inspire new opportunities for growth and development in the year ahead, ranging from exploring new textures of clothing or food to attempting a new outdoor activity with peers. Parents, give yourselves a hearty pat on the back for all you have accomplished and helped your children achieve!

Sibling's Corner

You Can Be a Huge Help to Your Sib! By Julie Wolf, PhD

Here's a question you may not have thought about: Who is the person who will be in your life longer than anyone else? The answer is probably your sibling! Siblings are usually in each other's lives from the time they are young children until they grow old. This means that you have an especially important role to play in the life of your brother or sister with autism. You can help them throughout their lives.

As a young child, simply playing with your brother or sister with autism can be really helpful. You are probably your sibling's most important playmate, especially during the COVID pandemic, and your sibling can learn so much just by playing with you. They can learn to take turns, to be creative, to share, and to be flexible about doing something someone else wants to do (and not always just what they want to do).

As a teenager, just hanging out with your brother or sister — watching a movie together, playing videogames, etc. — can help them learn how teens typically interact and just how much fun it can be to socialize with another person. As a teen, you are also the best person to advise your brother or sister on how other kids their age act. You can introduce them to the latest TV show that everyone is watching, tell them what things are cool and not cool, or help your parents select clothes for your sibling that won't be totally embarrassing for them to wear!

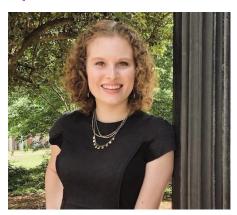
As an adult, you can continue to be an important social support to your sibling. As you get older, you may also decide that you want to take on more of a caretaking role for your sibling and can start talking to your parents about what that would involve.

While you and your sibling may not always get along (and sometimes they might drive you crazy!), you may also find that maintaining a lifelong relationship with your sibling is extremely rewarding and fulfilling, and that you can learn as

much from your sibling as they can learn from you.

Please <u>click here</u> to listen to Dr. Wolf's recent talk, "Siblings of Individuals with Autism Spectrum Disorder", to learn more about the sibling experience.

Q&A with a Lab Member



Introduce yourself!

Hi everyone! My name is Caroline, and I am a current Sparrow fellow in the McPartland Lab. I grew up in Georgia, and I am really excited to spend the next few years in New England.

Why did you join the McPartland Lab?

I spent time working as a peer mentor for individuals with autism throughout elementary, middle, and high school, and by the time I started college I knew that this was the field in which I wanted to work. In college I studied psychology and neuroscience and completed my master's degree in applied behavior analysis. I really value being able to work in both a clinical capacity and a research capacity, and I joined the McPartland Lab because this job provides a great mix of neuroscience research and clinical work with families.

Let's settle the dispute... who has the best pizza in New Haven?

In my opinion, One 6 Three has the best pizza in New Haven – their Potato Head pizza is especially delicious!

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

I am really looking forward to continuing to meet families and learn from all of the talented researchers and clinicians in our lab. In terms of projects, I am especially excited about our PELICAN EEG study because this population is not always well-represented in research. I am also looking forward to the Autism Biomarkers Consortium for Clinical Trials (ABC-CT) study beginning again soon!

Gardening Tips for Beginners

Spring is on the horizon so there's no better time than now to plan ahead for a garden. There are many types of gardens: flower, fruit, vegetable, and herb, to name a few. The first step is deciding which garden to plant. Here are tips to make a successful vegetable garden.

Pick the right location

Once you select what vegetables your family eats you need to pick the right location based on how much sun the plants need. Most vegetables, including tomatoes and peppers, need at least six hours of sun a day. You also want to pick a spot close to your house. This makes it easier to run out and pick what you need for a meal.

Prepare the Soil

Plants depend on the soil for nutrients, stability, and drainage. To grow your best garden, you should pull all weeds, till the soil, and add a layer of topsoil. You can also add organic matter, such as compost and manure, but never use fresh manure. It can harbor pathogens and will burn tender plant roots.

Seeds or plants?

Most garden vegetables can be directly seeded where they are to grow—lettuce, carrots, spinach, peas, cucumbers, and squash. Things that take longer to produce, such as tomatoes, peppers, and melons should be started indoors 6-8 weeks before planting them outside. This will ensure that

they don't take too long to grow, and you run out of the warm sunny weather.

Family fun for all

As the days go on there are chores that need to be done to make sure your garden is a success. Enlist your children to help water, weed, and tend to the soil. If they help from the beginning, they will

be so excited and proud to see their hard work grow into something delicious they can eat.



Are You Zoomed Out?

Does your workday routine leave you tired and irritable? Do you wish you had less video meetings? Here are five tips from Being Well at Yale to help with video fatigue.

Put away your devices

Each day take a moment to put aside all your devices and stretch, walk, or meditate. There are websites that have relaxing sounds or music that can help with this, such as MyLife.

Turn off/limit your camera use

Seeing yourself on your computer screen can cause anxiety as well as fatigue. You wonder if you look professional or if your background is distracting. Worrying about these issues can also make it difficult for you to focus on the conversation. If you have the option of not needing a video call opt for a phone call instead. If you must be on video change your view to speaker so that you don't see yourself as often or cover your screen with a piece of paper to make it easier to concentrate on what is being said.

Create a soothing work environment

If you can have your meetings outside do that. If outside isn't possible position yourself by a window so you can gaze outside from time to time. Surround yourself with a plant or succulents and a picture that brings out a happy memory. Keep your area clutter free so there are few distractions.

Less frequent or shorter meetings

Send out information ahead of a meeting so that the actual video time is shorter, even just by 15 minutes. Keep in touch with others via email in between meetings so that the actual video meetings can be compressed.

Limit multi-tasking

Making your brain focus on multiple things can be exhausting. While in a meeting turn off all notifications so you can concentrate on the meeting. Your brain will love you!

TDF – Bringing the Power of the Performing Arts to Everyone

TDF Autism Friendly Performances engaged children on the autism spectrum with three interactive online experiences last fall: a magic show and magic lessons with award-winning illusionist Kevin Spencer, and\A0 the original musical Santa and Little B: Zoom for the Holidays. These events were completely free for families and are available to watch online.

COVID-19 News from CT

The warmer weather is upon us, drawing people outside after being cooped up all winter. Our state's infection rate has remained low, so Gov. Lamont has updated his previous timeline of reopening our state and vaccine distribution.

As of March 19th, many venues are returning to 100% capacity including restaurants, salons, museums, and libraries. Movie theaters will remain at 50% capacity. Social and recreational gatherings at a private residence are now 25 indoors/100 outdoors. Social and recreational gatherings at commercial venues are now 100 indoors/200 outdoors.

The State of Connecticut will begin administering vaccinations for individuals on March 19th for ages 45 – 54 and on April 5th for ages 16 and up. Follow this link to check eligibility and find a vaccine provider near you.

We still must wear a mask and practice social distancing when out of our house. If you are experiencing any one of the following symptoms call your doctor and quarantine yourself.

- Fever > = 99.9F
- New cough
- New shortness of breath
- New sore throat
- New chills
- Sudden loss of taste or smell

Contact Us!

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



<u>Click here</u> if you would like us to contact you about participating in our studies or scan the QR code.

Follow us on Facebook and Twitter:



Yale Autism Program



@YaleAutism

The McPartland Lab stands in solidarity with BIPOC communities, 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.

Sent by The McPartland Lab Yale Child Study Center New Haven, CT (203) 737-3439 www.mcp-lab.org