McPartland Lab

NEWSLETTER

Greetings from the McPartland Lab!

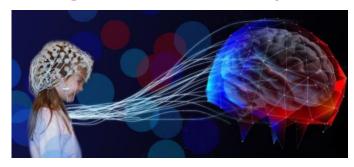
We hope you are all well as we enter the holiday season! This has been a busy and exciting time for our research group. In response to the challenges presented by the pandemic, we have reinvented just about everything we do. Our clinicians have developed new ways of working with children and adults to ensure safety by using novel technologies that allow "distanced" assessments. Our research team has completely rebuilt our laboratories to enable us to continue our research studies with updated safety protocols. We think that many of these innovations will allow us to do an even better job when the pandemic subsides! We have been so excited to see many of you in person these past few months, and we have been so grateful for your willingness to continue to partner with us in these new circumstances.

In this issue of our newsletter, we will highlight a new research study, introduce a member of our clinical research team, offer advice about navigating the educational system, and provide some ideas for celebrating this season. We were encouraged by the strong positive response we received to our last newsletter, and we welcome your input. Let us know what is most useful to you! Be well!

Best wishes,
Jamie McPartland



Exciting New Research Study



Many families involved in McPartland Lab research were introduced to our work by a large study we began in 2015, the Autism Biomarkers Consortium for Clinical Trials (ABC-CT). The ABC-CT marked the largest and most ambitious study of brain function in autism ever undertaken in the United States. Led by Yale, the study also involved sites at Duke University, UCLA, the University of Washington, and Boston Children's Hospital. Over the course of four years, the team worked with more than 280 families of children with ASD! We learned that two biological measures, or biomarkers, associated with looking at people's faces hold promise to help us understand how specific children with ASD might respond to specific treatments. The FDA has accepted these two biomarkers into their official qualification program – this is the first time the FDA has made this decision for a measure of autism or any neurodevelopmental condition.

This past July, we learned that we will have the opportunity to continue this line of research. The second phase of the ABC-CT will begin in the coming months and will allow us to conduct three separate studies. In the first study, we will follow-up with all the families we saw in the first phase. You will be hearing from us, and we can't wait to see you all 2 to 5 years after your original ABC-CT visit. The second study will provide us the opportunity to confirm our initial findings — this process, called *replication*, is an essential part of qualifying a biomarker with the FDA. The third study will test whether the measures we have developed are useful in younger children who are preschool aged.

Both <u>Yale</u> and the <u>National Institute of Mental</u> <u>Health</u> have recently highlighted this new research study. <u>Click here</u> to watch a short video of Dr. McPartland describing the progress of the ABC-CT.

We owe this success to you all! Thank you for working with us to develop new techniques to improve treatment and care for autism. You will be hearing from us...

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 |



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A Special Education
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As we all come to grips with the new temporary norms across our country due to the COVID-19 pandemic, it is critical that we understand and fully appreciate the impact this outbreak is having on special education and related services to our students with disabilities and their families. It is absolutely essential that families make informed decisions about the educational wellbeing of their children with disabilities by consulting with their local education agency. It is also equally important that families know their child's rights under the Individuals with Disabilities Education Act (IDEA) during this crisis situation, including their potential rights to compensatory education ("comp ed").

What is Compensatory Education?

Under the IDEA, local educational agencies (LEAs) are legally obligated to provide all children eligible to receive special education and related

services with a free appropriate public education (FAPE). If your LEA does not give your child the special education and related services they are supposed to be providing as forth in your child's IEP, your child may be eligible to receive compensatory education. Compensatory education is a compensation fund so to speak that helps your child catch up on lost time, hours, and related services for the duration of when your child was denied a FAPE. The amount of time and services that your child missed is referred to as compensatory education.

Is Your School District Closed, Open or Available for E-Learning?

If your LEA is closed and is not providing any educational opportunities to the general student population during the COVID-19 outbreak (i.e., school closure similar to a snow day), then your LEA is not legally required to provide services to children with disabilities during the same timeframe. The problem arises, however, when your LEA decides to offer online learning or elearning alternatives to the general student population, even if voluntary, while not offering the same opportunities for specialized instruction and related services to students with disabilities pursuant to their IEP or 504 Plan. In essence, your LEA, despite its best intentions, is providing educational opportunities to "some" students, but not others and therefore is not legally compliant.

The United States Department of Education (USDOE) issued guidance to LEAs on how to appropriately handle providing special education and release services to children with disabilities during the Coronavirus Disease 2019 ("COVID-19") outbreak. The USDOE provides guidance that your LEA "must ensure that, to the greatest extent possible" each student with a disability be provided the special education and related services set forth in the student's IEP or 504 Plan. The present concern that parents should inquire about is how their LEA is going to ensure that a student with a disability receives their IEP or 504 special education and related services "to the greatest extent possible" during the school closure. I anticipate this is where a plethora of compensatory education claims will need to be examined and provided once schools are back in session. The anticipated issues will include to what extent and amount of compensatory education will legally need to be provided.

How is Compensatory Education Calculated?

Generally speaking, the starting point in determining any compensatory education award is by showing when a parent knew or should have known about their child's denial of a FAPE. To put this into context, if your child's LEA decides to remain closed, but starts to offer e-learning programming for general education students, but not the same to children with disabilities, you should mark and enter that date down in a journal.

Next, you need to look at what educational benefits would have accrued during your child's denial of a FAPE period. This requires you to examine both the qualitative and quantitative benefits your child would have received had your child been offered a FAPE. There is no "cookiecutter" approach to this analysis since your child's education is specialized and uniquely designed to meet his or her needs.

Lastly, it is critical that you keep and maintain a sufficient record of your child's right to claims of compensatory education. An impartial hearing officer cannot appropriately determine the amount of your child's compensatory education claim unless you as a parent are able to provide the hearing officer or mediator with sufficient insight as to the precise type of educational and related services your child missed in order further to promote your child's progress as set forth in your child's IEP goals and objectives and service hours.

My firm and I are actively monitoring updates from the USDOE as well as following how LEAs are offering educational programming to students with disabilities, in order to ensure our children are being appropriately educated to the greatest extent possible during COVID-19 outbreak. For more information, please feel free to visit our website at www.fortelawgroup.com or listen to our podcast, www.letstalkspedlaw.com.

Practical Parenting Advice

Dealing with Unexpected School Changes by Christine Cukar-Capizzi, PsyD, BCBA



Children returning to school this year have an especially challenging fall experienced semester. While some students returned to inperson learning for the first time since schools were closed in March due to the COVID-19 pandemic, others have continued with virtual instruction or participated in a hybrid model of in person and virtual instruction. To further complicate matters, many school districts have had to quickly shift their instructional methods from in-person or hybrid models to virtual instruction due to COVID-19 exposures within their schools or towns. Often times, these changes have come about suddenly and with little warning, resulting in some children being required to switch to virtual instruction within a day's notice. Although this has been difficult for all children, dealing with these unexpected changes has proved especially challenging for children with autism, who tend to rely on structure and routines. Some children with autism can become very upset and dysregulated when presented with sudden changes in their routines, which has, in turn, resulted in challenges for their parents who try to support them.

Parents can help to support their children with autism to adjust to unexpected changes in routine by creating new "virtual instruction routines." Parents may find their children can benefit from external structures such as posting a schedule in the home that outlines the routine for virtual instruction days. Parents and children may find it fun to work together to develop these schedules by taking pictures of the child engaging in the

activities that are part of their virtual instruction days to include in their schedule. Furthermore, children can learn to associate virtual learning days at home as something positive, by using a technique from the science of behavior analysis called "pairing." Using pairing, particular settings or situations are "paired" with something previously reinforcing to the individual in order to make the new situation more appealing. A child may prefer in-person learning to virtual learning but can learn to associate virtual learning as a positive experience through pairing. For example, parents and children can work together to come up with a list of reinforcers that can be used on virtual learning days that their child would not typically have access to during in-person instruction. This could be things such as having a cup of warm hot chocolate to drink in between one of their online lessons, engaging in virtual learning while wearing cozy pajama pants and slippers, or working while cuddled up next to a favorite pet. Take some time to brainstorm what can be added or "paired" to the new situation that will make it more attractive for your child.

Sibling's Corner

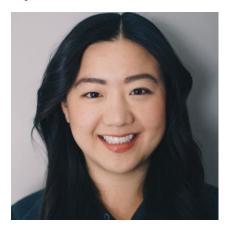
Managing Expectations by Julie Wolf, PhD

Sometimes kids who have a brother or sister with autism can expect a lot of themselves. You might see your parents worrying about whether your brother or sister is getting everything they need, and this might make you feel like you need to do everything correctly so they don't also have to worry about you. At the same time, you might feel like your parents have higher expectations for you than they have for your brother or sister with autism, and sometimes that can feel unfair. Helping out around the house and doing your best at school is important, and you can be a good role model for your brother or sister. But if you ever feel like there's too much pressure on you, talk to your parents. Stay calm and let them know how you feel, without blaming them or letting your emotions get the best of you. You could say something like, "I know you always want what's best for me, but sometimes there's a lot of

pressure." Or "I think my brother could learn how to do some of these chores. Maybe we can teach him, so he can help me out?" You and your parents can make a plan together about how to reduce any pressure you are feeling. Some kids find that just talking to their parents about how they are feeling can make a big difference!

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 Gloria, and I am a firstyear postdoctoral fellow in the McPartland Lab. I grew up in Michigan but have lived in various places in the US, including the Midwest, Southeast, and now the Northeast!

Why did you join the McPartland Lab?

After working as a camp counselor for individuals with ASD and developmental disabilities as an undergrad, I became determined to pursue a career path that would allow me to both understand and serve individuals with ASD and their families. This led me to complete my PhD in Clinical Psychology at Vanderbilt University. I love wearing both the researcher and clinician hats and am passionate about linking cutting edge research about the brain to interventions that can improve emotional health and wellbeing for individuals with ASD. The McPartland lab provides an ideal

setting for me to continue along this path. I'm excited to learn new neuroscience methods and collaborate with a team of scientists that shares my passion for serving individuals with ASD.

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

I can't say that I've tried all the different options to comment on a definitive winner. However, as an avid seafood lover, I am a fan of any kind of white clam pizza.

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

I continue to be excited about opportunities to learn from a team of talented researchers and clinicians. I also look forward to meeting families coming in for research visits, especially as the Autism Biomarkers Consortium for Clinical Trials (ABC-CT) study starts up again in 2021!

Survival Tips for De-Stressing During the Holidays

Holidays can be very stressful any year but with a worldwide pandemic the stress is over the top. Seeing loved ones and sharing memories may not be possible this year due to social distancing. Taking care of yourself should be at the top of your list. Here are some ideas for making sure you have an enjoyable holiday season.

Resist the urge to keep up with the Jones's

You wake up one morning and notice that all your neighbors' houses suddenly have wreaths on their doors, bright candles in their windows, and twinkling lights on their shrubs outside. When did this happen? Why are you so late to the game? Your heart pounds and you feel the need to race to drag your decorations out of storage and make your house looks like it just came out of *Better Homes and Gardens* magazine. You can't be the only house on the block that looks like the Grinch lives there. STOP!

If you feel that holiday decor is a must, make it simple. Buy a pre-lit artificial tree with pre-strung lights for yearly reuse. Choose wreaths made of pinecones, silk flowers, and artificial greens for a longer shelf life. And if you really love the smell of a fresh tree bring one home, add lights and a bow on top, and voila – you have a simply decorated tree with little stress.

Delegate what you can

Check local supermarkets and specialty food shops to see if they have holiday platters, dessert trays, even a completely cooked meal that you can pick up. It will make your time in the kitchen less and will be worth the extra cost. If you have older children enlist their help with cleaning the bathroom, vacuuming, and dusting. Time is very valuable and it's worth it to outsource what you can during this time of the year if you are able to do it.

Take time for yourself

Remember that you are only human and deserve to enjoy the holidays, too. Set aside time to take a walk, read a chapter or two in a book you have been trying to get to, meditate, or anything else you find relaxing. Just remember that it's important for you to be just as happy as you are trying to make others.

Perfect Apple Pie Recipe

<u>Pillsbury.com's</u> classic apple pie takes a shortcut with refrigerated pie crusts. Baked with a filling of fresh apples and warm spices, there is as much simple joy in preparing this pie as there is in eating it. This pie is easy to make and tastes delicious. Your guests will think that you toiled over creating it, when, in fact, it was smooth and quick. Whether you bake it for a holiday, a potluck, or as a special weekend dessert, this timeless pie recipe is guaranteed to spark joy.

Ingredients:

Crust

1 box Pillsbury™ refrigerated pie crusts, softened as directed on box

Filling

6 cups thinly sliced, peeled apples (6 medium)

¾ cup sugar

2 tablespoons all-purpose flour

¾ teaspoon ground cinnamon

¼ teaspoon salt

1/8 teaspoon ground nutmeg

1 tablespoon lemon juice

Directions:

Heat oven to 425°F. Place 1 pie crust in ungreased 9-inch glass pie plate. Press firmly against side and

bottom.



In a large bowl, gently mix filling ingredients; spoon into crust-lined pie plate. Top with second crust. Wrap excess top crust under bottom crust edge, pressing edges together to seal; flute. Cut slits or shapes in several places in top crust.

Bake 40 to 45 minutes or until apples are tender and crust is golden brown. Cover edge of crust with 2- to 3-inch wide strips of foil after first 15 to 20 minutes of baking to prevent excessive browning. Cool on cooling rack at least 2 hours before serving.



Staying Safe During the Holidays from the State of CT

The State of Connecticut has guidelines on its website (https://portal.ct.gov/Coronavirus) to assist in the prevention and testing of COVID-19. It is advised that during the holidays you only see people in your "pod". Forgo family gatherings to ensure that everyone stays healthy and safe. Remember to wash your hands or use hand sanitizer frequently if you are out shopping.

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

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

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.



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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.