



# PARENTING DURING A PANDEMIC

## A View Through An Autism Lens

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**O**n March 15, 2020, Gov. Charlie Baker ordered all public and private schools in Massachusetts to close for three weeks due to COVID-19. Parents of school-age children had to learn to juggle careers with remote learning, Zoom calls and no child care. College students were back home in their old rooms and not happy about it. Facebook pages were flooded with posts from parents struggling to get through the day. Parents were running on fumes, worried about the long-term impact of COVID-19 on their children's education and mental health. Sports seasons were cancelled, and graduations postponed. Three weeks turned into 13 months, and while many schools have reopened in some capacity, life is certainly not back to normal.

Like many parents, we worried about the impact of the pandemic on our children. Our youngest son's senior year of college ended abruptly, and we questioned whether our daughter should start business school. But the biggest challenge we faced was helping our 26-year-old son, Brian, who has autism, epilepsy and an intellectual disability, cope with how much his life changed. For families like ours, this pandemic was especially difficult for reasons many may not understand.

According to the Centers for Disease Control and Prevention, autism spectrum disorder is a developmental disability that can cause significant social, communication and behavioral challenges. While some individuals with autism have normal intelligence and can communicate, others have challenging behaviors and can be nonverbal. About 1 in 54 children has an autism spectrum disorder, which is four times more prevalent among boys than girls. What these statistics do not reveal

is that these children grow up and become adults.

Brian keeps active and thrives on routine. A 3-by-4-foot calendar hangs on his bedroom wall, and he writes his work schedule every Sunday night in erasable marker. His room is next to ours, and we can hear every deliberate stroke of his marker as he writes. It is worth noting that we are not allowed to ask him about his schedule. We are told to read the calendar.

Brian works at a HomeGoods four mornings a week and at two local farms a few afternoons and on Saturdays. He loves to draw and sells his art to family and friends. He redeems cans for the deposits and saves everything that he earns so that he can one day buy a farm like his ancestors. Brian likes to go to the movies, eat out, row and works out at a local gym with aides a few afternoons a week. He has benefitted from excellent schools and therapies and has made great progress but will never live independently. Brian is also lonely, wishes he had a girlfriend and does not believe



AY THURSDAY FRIDAY


8	9	10	11
15	16	17	18

22	23
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Go to Work

8	29	30	31
THU			FRI

JANUARY 1 1/364

1	2
1	

New Year's Day

4	5	6	7	8
11	12	13	14	15
18	19	20	21	22

Horse Farm

7	8	9
UES.	WED.	THURS.

01	02	03	04
08	09	10	11

14	15	16	17
14/352	14/351	15	17

he has a disability. We made peace with Brian's diagnosis years ago and believed we were ready for what life would bring. Nothing prepared us for COVID-19.

Brian receives state funding and has caregivers who go out with him in the community. He also has a social worker and a nurse that check in on him regularly. As COVID-19 began to spread, the workers could no longer come into our home, and many of the activities he enjoyed shut down. In early April, HomeGoods closed, and Brian could no longer work at one of the farms. His life came to a screeching halt, and he wanted to know when things would return to normal. So did we. One of Brian's preferred activities in the beginning of COVID-19 was to make lists of what he would do when it ended. He even posted it on Facebook. Many friends told us they felt like Brian but hesitated to admit it.

Brian knew about COVID-19 and started to follow the daily rates of infection on social media. He practically bathed in hand sanitizer, stockpiled disposable gloves and hoarded masks. He created his own personal protective equipment station in a corner of our kitchen. It includes boxes of disposable gloves, more than 15 masks and a handwritten note that reads "PLEASE DO NOT TOUCH MY BLUE MASKS WITHOUT ASKING ME ON THE PHONE FIRST PLEASE." Everyone in our family knows better than to ignore this request. Brian did not come within 6 feet of anyone for a year and never left the state. He asked us every day if there was good news and wanted to know when COVID would go away. We had no answers and wondered how long we could go on like this. One day, Brian hung a sign on the fridge that asked us to text him if the governor called with information about a vaccine. It hung there for months. Somehow, we muddled through as a family, but it was heartbreaking to watch Brian regress.

Fortunately, we could use telehealth services to stay in touch with Brian's doctors. He always looks forward to his appointments and did surprisingly well with Zoom appointments. It was reassuring to discuss our concerns about Brian's changes in behavior and struggles with being at home with his psychiatrist. Brian could articulate his frustration with the pandemic, and his doc-

tor validated what he was feeling. These sessions were so helpful, and I hope they continue.

A particularly painful time for me was when I had to complete a COVID-19 disability form in case Brian was hospitalized with the virus. I was horrified to learn that the form had to be filled out because I would not be allowed to go into a

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hospital with him if he needed care. One question asked the following:

"If while you are in the hospital you can't breathe on your own, do you want a machine to help breathe for you?"

"Do you want it at all?"

"Do you want a trial to see if it is helping? Do you want it for as long as is needed?"

The next question asked if he wanted his doctor to try to restart his heart if it stopped.

I cried as I filled out the form.

When Brian was in close contact with someone with COVID-19, we reached out to a medical provider for advice. She knew he had autism and still insisted that he isolate and let us know his symptoms. There was no way that would be possible. Instead, the whole family quarantined for eight days. Thankfully, everyone tested negative twice. We signed up for a new doctor the next week. He happens to be the parent of a son with autism. Brian met with him in person and told us he likes his new doctor. No small victory.

Other friends shared their own struggles. Some of them had children residing in residential settings. These parents were unable to visit them for months. Others learned that their chil-



dren had COVID-19 but could not see them due to visitation restrictions. One friend brought her son home from a residential program out of fear that if he became sick, he could not survive due to other medical conditions. When day programs closed, parents had to create their own programming for their adult children. One mother I know started a daily baking program in her house for her son. They created some beautiful cakes together. My friend's son could not accept the fact that movie theaters were closed. In the beginning of the pandemic, he called his favorite theater at least 30 times a day, hoping someone would answer. His mom took him to the theater and helped him accept that theaters were closed and that no new movies were being shown.

There were also moments of grace. When vaccines became available, prioritization for adults with disabilities was not clear-cut. Brian saw his friends with their vaccine cards on Facebook and told me I was a bad mother because they had vaccines and he did not. He did not understand why certain friends with autism were vaccinated but he was not. Quite candidly, neither did I. During one of my more difficult afternoons, I called a government official to ask why my son could not get vaccinated. We spoke at length about the vaccine rollout, and she explained that she would continue to advocate on behalf of adults with disabilities. Although I didn't change the outcome, I felt listened to as a parent.

After I hung up, I reached out to my friends Maura Sullivan of the Arc of Massachusetts and Michael Borr of Advocates for Autism of Massachusetts (AFAM). When I explained my frustration with the prioritization process for individuals with intellectual disabilities and their parent-caregivers, they reached out to members of the legislature and drafted letters to government leaders seeking a solution. Their efforts resulted in more than 3,000 letters being sent to Baker and Secretary of Health and Human Services Mary Lou Sudders, asking for vaccines for adults with intellectual disabilities. Eventually, the prioritization was modified, and more vaccines were available.

Schools and programs that work with individuals with autism often went above and beyond the call of duty. When staff at Melmark New England, a day and residential school for students with

autism, learned that a staff member had tested positive for COVID-19, they opted to quarantine with the students with autism at the residence for eight days. Melmark parents delivered meals every day and organized a car parade to celebrate the end of quarantine.<sup>1</sup>

In March, a COVID-19 vaccination clinic was hosted at the Lincoln Financial Field in Philadelphia by the Eagles Autism Foundation in partnership with Divine Providence. Vaccines were administered to more than 1,000 individuals with autism and their families. Doug Lurie, owner of the Philadelphia Eagles, has a brother with autism and formed the Eagles Autism Foundation to raise money for research and programs to help better understand autism.<sup>2</sup>

Mass Advocates for Children, a child advocacy firm in Boston where I do pro bono legal work, created a COVID-19 Information Clearing House for families trying to ensure their children receive the educational services they are entitled to. It started virtual monthly chats as a way for parents to connect with each other and to discuss concerns with special education experts and lawyers. Mass Advocates for Children also provides guidance to parents about compensatory services and summer school.

And yet, families continue to struggle. Many day programs have not reopened, and those that have operate at half capacity and cannot take participants out in the community. There are also staff shortages. Many of the jobs that adults with disabilities had before the pandemic no longer exist. Social outings could not resume until more

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people are vaccinated. It is difficult for adults with disabilities to fully understand why things cannot return to normal.

I am happy to report that Brian got vaccinated at a Council on Aging Clinic in a town nearby. After receiving his first shot and waiting for 15 minutes to pass, he called his father on his cell phone and told him he finally got his life back. Later that day, his sister and her fiance came for dinner to celebrate their engagement. He had asked her to marry him a few days before. They had called family members to share the news but

had not made any public announcement. While sitting together talking about wedding plans, they asked Brian to share their news on Facebook. Brian was the ideal choice as he has quite a social media following and posts regularly on Facebook and Instagram. His posts are known for lots of emojis, and he lives for likes and comments. He posted a beautiful photo of them together with the words “Congratulations to my sister and her future husband and my new brother-in-law. Cheers to you both. Wish you lots of happiness and love. So very excited about this news.” It was wonderful to have good news to share. Many people agreed. Brian’s post received 142 likes and 54 comments. It was a good day for our family.

**ANN E. GUAY** has worked as an attorney in private practice and was a policy analyst at Massachusetts Advocates for Children, where she

now volunteers as a pro bono attorney for military families. She serves on the executive committee of Advocates for Autism of Massachusetts and the boards of several autism programs for adults.

**NOTES**

1. Genevieve DiNatale, “Melmark Quarantines Students with Staff 8 Days After Coronavirus Exposure,” *Andover Townsman*, April 21, 2021, [https://www.andovertownsman.com/news/local\\_news/melmark-quarantines-students-and-staff-8-days-after-coronavirus-exposure/article\\_e8fc4a2a-04a1-5ad4-af9a-009154baed7d.html](https://www.andovertownsman.com/news/local_news/melmark-quarantines-students-and-staff-8-days-after-coronavirus-exposure/article_e8fc4a2a-04a1-5ad4-af9a-009154baed7d.html).
2. Maddie Hamman, “At the Eagles’ Stadium, a COVID-19 Vaccination Clinic Designed for People with Autism: ‘We Need to Meet Them Where They Are,’” *Philadelphia Inquirer*, March 27, 2021, <https://www.inquirer.com/health/coronavirus/covid-vaccine-philadelphia-autism-disabilities-eagles-20210327.html>.

PAUSE. BREATHE. HEAL.

## *Courage in Uncertainty*

For just this moment, bring your attention to your breath.

**INHALE** deeply and settle yourself into your body.

**EXHALE** the stress and tension you feel.

In these days of uncertainty, a moment to pause is both a gift and a necessity.

**GENTLE YOUR BREATHING**, your gaze and your heart as you consider:

Where have I found courage in the past days?

**THINK FOR A MOMENT.**

In these days of uncertainty, where have I found courage?

*(Pause to consider)*

**DWELL** in the courage you have found and bring it with you into the rest of your day.

Even now, God is with you, as near to you as your breath. Continue giving yourself the gift to pause, breathe and heal, knowing you are not alone.

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*Our God himself goes before you and will be with you; he will never leave you nor forsake you. Do not be afraid; do not be discouraged.* **DEUTERONOMY 31:8**

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