

Community Conversations - New Jersey's Covid-19 Project

"Bright Spot"

The pandemic was difficult for many, but unusually so for students with special needs. In March we had so much to look forward to: my son Patrick, a 21-year-old on the autism spectrum, was about to graduate from high school; he was accepted into an adult day program; his school's employment training staff secured a job for him in a restaurant; and the pastor at our church offered to hire him to continue his volunteer work there after graduation.

And then the rug was pulled out from under him.

Whatever worries we had about getting sick or running out of supplies were trivial compared to the anxiety I felt over how the quarantine would affect Patrick. There was so much he is not capable of understanding, or expressing. Routines are paramount to his days - and suddenly there were none. No school, but also no swimming, no restaurants, no stores.

He could not comprehend why school was closed. He crossed off the day on a calendar every night and begged to count down the days until he could return. It was heartbreaking to have no answer for him. My husband came up with the brilliant idea to tell him "100 days til school". The magical 100^h day was sometime in the summer, after his graduation. After all, this would never last that long, would it? For a while this worked well, and we heard him faithfully counting and turning the pages of his calendar before bedtime every night. After a few months we realized that he would never have a chance to return to his classroom.

Although he eventually adjusted to some limited virtual lessons, it was very frustrating at first. I unpacked worksheets and activities from years of boxes hiding in closets. We began a rough routine of desktop work, even if they were very simple lessons. Thankfully his ABA (Applied Behavioral Analysis) therapists were able to conduct his sessions remotely, three times a week. We walked every day - around the loop in front of our house, on deserted high school tracks, on empty college campuses. We gathered rocks and painted them.

After a most joyous drive-by graduation ceremony, the days grew longer and emptier. While schools could still have remote lessons for some special ed students during the summer, the adult day program was not to open for many more months. Many families of adults were essentially doing the job of a day program themselves, and so the ██████████ granted an exception for a parent to be paid as an SDE (self-directed employee). Soon there was a catch: employees would have to write down what we did each day in support of the adult's goals.

It was an annoying task - every day seemed the same, yet we were not allowed to cut and paste. I found that if I did not keep up with the notes, I would not remember what we did. How many different ways are there to say that you sat next to your son, in front of a Chromebook, hoping he could pay attention to it instead of looking to you for a hint? Or that it was so much easier to let him spend hours in his room on his Ipad?

But I was actually getting paid week after week, and forced myself to keep up. Soon, I found that I was adding a new little activity here and there so that I could write it in the timesheets. The daily logs became our Late-Covid Diary. I look back now on the first few months of entries, and I discover some sweet moments and some details that are surprising. The items are mostly mundane to us - but they show just how different our daily challenges may seem to most families.

*Sunday 7/19/20 Drove to Church for outdoor mass. Supervised his volunteer work of rearranging the orange traffic cones. Drove to shopping center, where **he entered a store for the first time** in months. Prompted him to pull up his mask repeatedly, but cooperative. Practiced social distancing. [To ensure social distancing in the parking lot, the cones are used to block out every other space. We volunteered Patrick to take on that task. This became his only structured activity outside the home for many months.]*

Thursday 7/23 He missed his virtual Social Group because he stayed in bed too late - tried to get him going. Worked on getting him ready in time for ABA session. Monitored, helped get materials, redirected to computer, prompted him to stay on task, timed how long he kept mask on (clear face shield). Went to walk at ██████████ campus - for exercise, to practice social distancing and wearing a mask, and to reinforce finding the crosswalk and looking for cars. [Many families report that without the routine of physically going to school or a program, their child developed erratic sleep schedules.]

Saturday 7/25 We worked on household chores- he took out garbage and put dirty dishes in sink. Brought him into pharmacy to pick up only 1 item. He was compliant with pulling up his mask (bandana) but did not keep it on consistently. Practiced selecting appropriate footwear and tying sneakers. Walked almost a mile around HS track. After dinner he requested a DVD (not able to set it up to play on his own).

*Friday Aug 14 Morning tutoring session on language and math. During the break we danced to the song "Happy" with the Minions characters. Walked the loop. Packed for **beach trip**, drove to NY. Walked to ocean. Practiced applying sunblock, staying close to caretaker while in the water. [Mid-August was the first time he agreed to go to the beach. He had been too anxious before then.]*

Thursday September 17 Conducted a "work with Mom" session, covering calendar, copy address, connect the dots and color picture, match digital to clock time, simple addition. Tried a new lesson on recognizing value of paper money. Prepared for social group but was canceled.

Wednesday Oct 7 Took a trip to the drive-through Jurassic Quest park. Had to prepare him to sit in the front seat to see the figures better, but could go back to his regular seat afterwards.

Saturday October 31 Swept leaves. Walked the loop. During a visit with relatives, sat by firepit. He was eager to put out the fire with the garden hose. Prompted him to wait until the wood was all burned. Drove to get takeout dinner. Drove to church for volunteer job. Guided him to sit with family together to watch an episode of The Mandalorian. He became engaged in looking for "Baby Yoda" and remained with us. [This was the first time ever that all four of us sat together to watch an entire show.]

Thursday November 19 Today is Patrick's 22d birthday. Extended family usually celebrates at Thanksgiving, with a turkey-shaped ice cream cake. He gets the drumstick. We will not host Thanksgiving this year. Today he can choose which takeout to get for three of us. He can show his birthday gifts at the virtual social group, the only few minutes of structured activity for the day

Conclusion

When I was pregnant with Patrick, I had to get a more detailed ultrasound, due to my age. Although there were no obvious problems, the doctors looked for certain markers. They told me my baby had "a bright spot on his heart" - certainly frightening to hear. There were vague words about the correlation of these observations to conditions such as Down Syndrome.

The past eleven months are a blur of lazy days, cozy in our home, punctuated by happy moments with Patrick. He is the bright spot in my heart.

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