

Community Conversations

Answers to Guiding Questions by Gina Hookey

March 17, 2021

Evan is in a day hab work program, working at WaWa 2 hrs/day, 1 adult sibling not living at home and some help from former teachers.

1) Evan has been home since March, remote learning does not work for him. We have been juggling his care, work, dealing with outbursts and confusion and major changes in his schedule. He is very driven and motivated by his schedule that now all of a sudden was 'blank'.

We had help with a caregiver 1-2 times per week to take him on walks etc as he does not behave with us and bolts or runs away from us. We expect post covid challenges to still be the changes in his routine and schedule. One of the greatest disappointments was not having him active and out of the house. He does like people and goes up to them so that was even harder because people got 'scared' upon his approach.

2) Daily life: one parent going into an office, one working remote from home, making arrangements for some care for him during the week, taking the dog to the office so he can be walked since Evan can't be left alone and is tries to enter other people's home if we take him to walk the dog. The one good thing that came from him being home- he was dealing with a serious GI issue that we had taken him to the Dr. and done testing, we would have done further testing but after he was home for a month it all cleared up. The day program had to do an investigation and we learned he was being given something he should not have been given as he is on a strict diet. We found joy listening to music, watching Jeopardy as a family. Evan got to have more interaction with the dog. I would chat with family members and friends to commiserate.

3) Evan uses his ipad and likes to watch TV. We did not get his ipad from the program. The major problems we had - when the power went out or surged he would throw major tantrums that were hard to control. The 'special reports' (of which there were SO many this year) that interrupted his TV show would also throw him into a fit.

4) No one in the family contracted covid. We did not have a problem getting a test. I spoke to his neurologist re: covid and vaccine as Evan started having seizures again during the time at home. He said he recommends the vaccine for him. Evan is being vaccinated.

5) Evan learned to wear a mask, I first fashioned a band on it so he could drop it down and it would hang around his neck, and later found lanyards specifically made for masks. I bought him all types of fun masks and he got to choose which one to wear. As stated above the social distancing was a huge problem because he loves to go up to people and strangers, shake hands and say 'hi'. This upset people as you can imagine. He bolted into a dance studio once (they forgot to lock their door) he wouldn't leave and we tried to get him out unsuccessfully and they had to call the police to help escort him out- this was a low point for sure. I would print pictures and social stories for him to try to help him understand what was going on.

6) I do believe people with autism were not a priority with the emergency response - the state gave preference to smokers and overweight people for the vaccine but did not have an 'autism or a developmental disability' listed on the medical conditions, just neurological and that confused a lot of people. It was helpful that the state compensated day programs financially and allow family members to be paid caregivers. NJ could have opened up the day programs before Oct. as I believe day care and other facilities opened in June. Then to close after such a short time and not to open in Jan as they had stated - schools for autism were allowed to open so the explanation that this 'population' was under different guidelines didn't make sense. I don't think the state realized the hardship having an adult autistic person home all of this time really created especially with working parents. Also the state said he could continue to work at WaWa (which he could not because the contract was with his day program) but what sense did that make?? A store open to the public would be safer for him than a day program???