Companion materials to “Chapter 12: Be True to Your School”

The Advocacy Files

Letters, emails, and lessons from two and a half decades of advocating for autistic kids — and eventually for myself.

Cyn Snow

Before You Read

A note about how to use this document.

The letters, emails, and lessons in this document reflect my personal experience advocating for my family inside specific schools, with specific clinicians, in specific situations, over a specific span of years. They are not professional advice. They are not legal advice. They are not medical, educational, psychological, or therapeutic guidance.

I am not a lawyer, doctor, special education attorney, clinician, IEP coordinator, or disability rights professional. I am a parent who learned to advocate by doing it — by trying, failing, succeeding, and writing things down.

What worked for my family in our specific circumstances may not work for yours. Federal disability law (IDEA, ADA, Section 504), state law, district policy, school culture, your child's profile, your own profile, the people on your team, and dozens of other variables will shape what works for you. Take what's useful here as a starting point — not a prescription.

For your own situation, please consult appropriate professionals:

- An education attorney or special education advocate for legal questions about IEPs, 504 plans, manifestation meetings, suspensions, or other disability-related school matters.
- A clinician, psychiatrist, or therapist for diagnostic or medical questions.
- A disability rights organization in your state for information about your rights and your child's rights.
- An HR or ADA coordinator for workplace accommodation questions.

If something in this document is useful, take it. Adapt it. Make it yours. But please don't treat it as a guarantee, a prescription, or a substitute for the professional support your specific situation may require.

The author and publisher disclaim any liability for outcomes resulting from the application of materials in this document. Use at your own discretion, with appropriate professional consultation.

What This Document Is

These are the companion materials to “Chapter 12: Be True to Your School” in *And Then There Were Four*. The chapter tells the story of advocating for two autistic sons inside the public school system. This document is what's underneath the story — the actual letters, the actual emails, the actual interventions, and the lessons I pulled out of them across two and a half decades of advocacy.

If you have an autistic kid in school, or a kid heading into school, or an adult child still navigating the system, or yourself navigating an ADA process for the first time — this document is a working playbook. Real templates. Real exchanges. Real lessons I had to learn the hard way so you don't have to. It is, frankly, the most useful set of materials I know how to give you.

What you are about to read is a collection of real letters, real emails, and real interventions written from 2002 to 2025. The names of teachers, doctors, peers, and case managers have been altered by a letter or two to protect their privacy. Everything else is as it happened — including the parts that are hard, the parts where I got it wrong, and the parts where the system failed and we had to recover.

This document exists because a chapter is a narrative, and a narrative has to keep moving. Specific letters that took me hours to write, specific accommodations that took me years to figure out, specific email exchanges that show exactly how to push back on a defensive teacher or recover from a misunderstanding — those don't fit cleanly inside a chapter. But they are the artifacts that made the chapter possible, and they belong in the hands of the people who need them.

If you are an autism parent, an autistic adult, an IEP coordinator, a teacher, or a clinician trying to learn what good advocacy looks like — this is for you. Read it cover to cover or use the headings to find what you need. Take what works. Adapt the templates. Write your own letter and put your own kid's name in it.

The work is hard. The work is worth it. The work compounds. Two and a half decades of it is in this document. I hope it shortcuts some of yours.

A Word About These Letters

If there are three things I want every autism parent — and every autistic adult — to take from this section, they are these:

1. Write the letter yourself.

Don't wait for your doctor to write it. Don't wait for the school to write it. Don't wait for the HR department, the IEP coordinator, the testing service, or the well-meaning case manager to write it. They don't know what you need. You do. They don't know how your kid melts down, what triggers your sensory shutdown, why an open testing room is a non-starter, or why a four-hour exam with no breaks is going to end the same way every time. You know.

So write the letter. Name the diagnosis. Spell out the functional impact in concrete language. List the specific accommodations and tie each one to a specific need. Make it impossible to misunderstand. Then hand it to the clinician — or the psychiatrist, or the OT, or the doctor who's known your kid for years — and ask them to sign it.

Most of the time, they will. Because they don't want to draft it from scratch either. You've just done their job for them. They'll edit a sentence, add their letterhead, and sign.

Every letter in this section after the first one was written by me. Brian's 2010 disability attestation? I wrote it. The 2023 ADA request for myself? I wrote it. The 2025 testing accommodation letter for Evan? Evan and I wrote it. The doctors signed. The accommodations were granted. Every time.

The only letter in this section I didn't write is the very first one — the 2002 OT letter that taught me how. After that, I never waited again.

2. Volunteer in the building.

If the letters are the formal channel, volunteering is the informal one. And the informal channel is where you build the relationships that make the formal channel work.

Sign up for the field trips. Walk with the recess group. Help out at the book fair. Chaperone the dance. Show up. Not because schools love a “good parent” — they do, but that's not the point — and not so the teachers see you as cooperative — they will, but that's not the point either. The point is to be in the building.

When you're in the building, three things happen at once. You see your kid in their environment without it being a Big Deal. You meet the teachers and aides and counselors who actually run your kid's day, on their turf, in casual moments where they tell you things they'd never put in writing. And you become a familiar face — which means that when you need a favor, you're not a

stranger walking in cold with an ask. You're the parent who walked with the recess group every Wednesday in April.

Schools are systems, and systems run on familiarity. Every hour you spend in the building deposits something in an account you'll cash later. I started volunteering with a Wednesday walking group at the elementary school in April 2008, while we were still figuring out where Brian would go for middle school. By the time the placement meeting happened, half the staff knew me by sight. That mattered. It always matters.

Being in the building also means you find out things the building doesn't tell you on purpose.

In January 2009, I emailed Brian's middle school teacher to confirm I'd be chaperoning a field trip to the Maryland Science Center. His reply, which I have kept all these years because I could not quite believe it:

> *I just returned from Disney World last night so I'm sorry for not being in touch more. I'm glad that you can chaperone for the field trip because I received a list of students that were suspended this quarter from the office and Brian was on the list.*

That's how I learned Brian had been suspended that quarter. Not by phone call. Not by letter. Not in a meeting. In passing, in a field trip logistics email, sandwiched between a teacher's vacation and a chaperone assignment.

The lesson was clear. Schools will tell you what they have to tell you, eventually, sometimes. They will not always tell you what you need to know on the timeline you need to know it. Be in the building. Read every email twice. Ask the questions other parents don't have to ask. Assume nothing.

I asked him in my reply if I was supposed to chaperone a normal group of about seven students, or just be — and this is the word I used — Brian's Keeper. He didn't catch the bitterness in it. I caught it for him.

Two days later, the school psychologist sent a different kind of email. Brian had walked out of Science class that morning — appropriately, she noted — and spent fifteen minutes processing in the boys' bathroom. She checked on him. When he came out, he told her he was upset about me chaperoning the upcoming trip. She walked him through it. She told me about the two infractions he'd received recently — one for something he said to a classmate, one for an inappropriate comment about Tinkerbell during a teacher's vacation slideshow. She told me he'd missed the lunch detention that day because he was processing with her, and she'd already planned to prep him for it on Tuesday so there wouldn't be any surprises.

That email is the other side. The Disney World email is what happens when a school doesn't see your kid. The bathroom-and-Tinkerbell email is what happens when it does. Same week, same

kid, two completely different schools. Being in the building means knowing the difference, and giving more of yourself to the people who see what you see.

3. Thank the people who show up for your kid.

This one sounds obvious. It isn't.

Teachers, aides, counselors, OTs, bus drivers, lunch monitors — the people in the school building who are doing right by your kid — almost never hear about it. They hear from parents when something is wrong. They hear from administrators when there's a complaint. They don't usually hear from anybody when they're getting it right, because parents who are getting what they need have other fires to put out.

Break that pattern.

When a teacher handles your kid well — really well, the kind of well that requires her to think on her feet in front of twenty-five other children — send a thank-you. Send a real one. A card. A gift card to a bookstore. A box of chocolates. Something that lands in her mailbox and says I noticed, and what you did mattered, and I am paying attention to the people who pay attention to my kid.

I did this often. In one case, Brian's fifth-grade teacher, Ms. Goetzler, handled a moment where Brian — taking her instruction to "baffle her" literally — shoved her in class. She didn't escalate. She walked him through it. A few weeks later, after another small moment where she did right by Brian, I sent her a Borders gift card and a box of chocolates. Her thank-you note back to me said:

> *Brian has been doing wonderfully in the classroom. He listens and is open minded to my thoughts as well as his peers. I am proud of how he is making such a conscious effort to control himself and improve.*

That's what a teacher writes when she's on your team. And she was on Brian's team partly because she was a great teacher, and partly because somebody — me — had bothered to notice she was a great teacher and tell her so in writing.

Schools are systems. Systems are made of people. People remember being thanked. The next time something hard comes up, the teacher who got the chocolates is the teacher who picks up the phone faster, stays a few minutes later, advocates one room over for your kid's accommodation request, or writes you a thank-you note you can frame on the wall when you need a reminder that this whole thing is worth doing.

Send the chocolates.

Together, these three things are the playbook.

Write the letters. Be in the building. Thank the people who show up.

The letters tell the institution what your kid needs. The volunteering tells the institution you're paying attention and not going anywhere. The thank-yous tell the people inside the institution that you see them as people, not just functionaries. All three are forms of advocacy. All three compound over time. None of them works as well alone.

You don't have to wait for permission to do any of them.

Letter from Brian's Occupational Therapist

August 2002

This is the earliest document in the file, and it's the one where I was still learning. Brian was about to start first grade. He'd been in occupational therapy for two years. I didn't yet know how to advocate for what he needed in school — I barely knew what he needed.

I leaned hard on his OT, who knew Brian better than the school did and better than I did in some ways. He wrote this letter to support whatever accommodations the school would need to put in place. Reading it now, I can see the bones of every advocacy letter I'd write over the next twenty years. The OT taught me what to ask for. I just got better at asking.

* * *

Brian's occupational therapist had been seeing him for two years by the time he wrote this letter. He observed that Brian was a very smart little boy who communicated well with his therapist and made his needs known. Brian had shown tremendous improvements in therapy. He was able to sit at a desk, but had low muscle tone, which meant he could not maintain appropriate posture for long periods. His endurance would not hold up over time, which the therapist identified as an area of concern.

The therapist explained the effect of fatigue on function. He recommended that Brian not sit at a desk for extended periods. He noted that teachers should watch for Brian to start wiggling or moving around in his seat — this would be an unconscious process of sensory seeking, his system trying to get the sensory input it wasn't receiving for adequate posture and alertness. When Brian's focus shifted to sensory-seeking activities, his level of alertness would likely decrease, and his ability to follow verbal instructions would be compromised.

The therapist also noted that Brian had come a long way with his ability to write and complete fine motor tasks. He had difficulty attaining a perfect pencil grasp, and his writing abilities might be somewhat slower than his peers.

Recommendations

- Brian will need movement whenever possible.
- He will need frequent breaks from his seat to help him remain focused on the tasks he is engaged in.
- He will need to utilize recess breaks to get the sensory stimuli his system needs to stay at an appropriate level of arousal.
- When he is seen leaning over his desk, he needs to get up and move in order to get the sensory input his muscles and joints need.

- He will need to be told ahead of time about what is expected of him. Rules and expectations need to be given ahead of time, just as they are given with other children.
- He works well with a good system of rewards. This will be effective in helping him keep to the structure of classroom activities, and also in relation to his regard for safety and impulse control.

The therapist closed by offering to provide any additional information the school might need.

Placement Request for the 2006–2007 School Year

April 2006

A documented example of early advocacy in action. This was submitted as a formal placement request for Brian outlining specific learning needs, environmental considerations, medical concerns, and peer dynamics. By 2006, I had four years of OT recommendations and school experience behind me. I was no longer just relaying what clinicians said. I was making the requests myself.

* * *

Environment

- Firm but fair, predictable, and calming.
- A teacher Brian can earn trust with — not an authoritarian "because I said so" type.
- Reference his current teacher's recommendation; she and Brian see eye to eye very well, and we want someone with a similar calming influence.

Start of Day

- A quiet start.
- Place him in a calm, quiet space to begin the day rather than a regular homeroom — regular homerooms are too chaotic for him to start in.

End of Day

- Keep him out of the regular afternoon carpool — too unstructured and chaotic.

Peer Considerations

- Sue and Sally have input on a couple of peers Brian gets riled up around — avoid those matchups, separate those peers.
- Place him in a class with Aidan, who has a calming influence on him.

Signed April 2006.

Letter to Dr. Forbis, Former Psychiatrist

February 2008

This one is a snapshot of the gap between systems. We had just moved from Georgia to Maryland. Brian was 11 and not even close to ready for a full school day. The new school district had approved 30 days of home and hospital instruction — partly because Dr. Forbis, his Georgia psychiatrist, had recommended it. But we hadn't landed a new psychiatrist in Maryland yet, the school needed forms filled out now, and the earliest opening at the specialty clinic we'd finally tracked down was two months away.

So I did what advocacy moms do — I asked the doctor we used to have to do one more favor for us. Dr. Forbis came through. This letter went over with the home and hospital application by fax.

* * *

Dear Dr. Forbis,

Hi there — thanks for your help with the home and hospital application. We had a meeting with the home and hospital representative and we have been approved for 30 days of home and hospital. I think they approved it partially because you recommended it, and also because we are waiting for Brian's psychiatric review.

The school has scheduled a psychiatrist to come observe Brian on February 19th at school, and that observation will be followed by an in-office evaluation by a Dr. Kevin Harris. Dr. Harris works with the new district's schools but doesn't accept private insurance. So we've been trying to find a private doctor for Brian.

To that end, I have found some success today. I was finally able to get an initial appointment at MSA, The Adolescent Clinic. Alas, their first available appointment isn't until April 11th. The good news is that they specialize in difficult pediatric cases — many of their cases have been referred by Hopkins or Kennedy Krieger as especially difficult. They also offer an intensive after-school treatment program. I can't wait to learn more.

The bad news is that we won't see them until that April appointment, which leaves us with two upcoming psychiatrist appointments and no one to fill out the transition plan the school needs to have completed now.

Would you kindly fill out one more form to answer their questions? Brian is not currently in therapy but is still taking the same meds he was taking when you saw him last. He hasn't been taking atenolol, but he is taking gabapentin and fluoxetine.

As far as his eventual return to school: his teacher Rebecca Bell and I believe that for the indefinite future, Brian must remain either on home and hospital or alternatively on a truncated

day. I guess I'll pick up whatever he's not getting in school with homeschool supplementing, but in no way is he anywhere near ready for a full school day. His maximum patience and ability to function in that environment is about four hours. His impulsivity and frustration tolerance make it impossible for him to do more than that.

Thanks for your consideration. We really miss you.

Sincerely,

Cyn

Between the Letters: April 2008

The formal documents tell you what we asked for. They don't tell you why. The why was in the small moments — the ones that didn't make it into IEPs but shaped every line of them.

One afternoon, Brian's reading class was doing an activity outside. The teacher, Ms. Goetzler, told the kids to “baffle” her. Brian shoved her. He wasn't being defiant. He was being correct. Shoving Ms. Goetzler would in fact baffle her. She said the word. He delivered. The trouble was the school had a rule — we don't touch people — that overrode the assignment Ms. Goetzler had just given.

Brian's elementary school teacher, Rebecca Bell, walked him through it later: yes, you're right that shoving her would baffle her, but the bigger rule is the social one. Brian said OK. He filed the rule. The cave-man drive to bump and crash stayed.

That same evening I emailed Rebecca:

> *He'll tackle me or Ed, or turn a hug into a wrestling match, all without processing that it may be uncomfortable to the other person. It's his thing — kind of cave-man style.*

That's what the supplementary aids list that follows was actually for. Not the language. The kid behind the language.

* * *

A week later, the advocacy looked different. We were picking a middle school. Two options were on the table, both with the right programs. One was twelve minutes away. The other was seventeen. I emailed Rebecca and the team and ran the math:

> *Mapquest says that EM is 12 minutes each way (for an approximate daily commute of 48 minutes total) vs. MH, which is 17 minutes each way (which totals 68 minutes daily). Over a week's time, that's 100 minutes more commute time going to Murray Hall. A big difference in both time and gas.*

The clinical case for the closer school was strong on its own — it was the school Brian's psychiatrist had named by name. But I also had Evan to shuttle to elementary school, a job, and a household to run. So I made the case the school could most easily approve: the math one. Sometimes advocacy is a diagnostic argument. Sometimes it's a MapQuest printout.

Supplementary Aids and Services

2008

This is the laundry list. The actual operational ask. Not a letter, not a polished narrative — just the list of supports we needed in place for Brian to function in a school day. Every item came from somewhere real. Every item had a reason.

By 2008, I had enough advocacy reps under my belt to know that vague requests get vague results, so I spelled out every accommodation in concrete, implementable language. If a school staff member couldn't read this list and know exactly what to do, it wasn't specific enough.

The list also wasn't drafted in one sitting. It was built incrementally, through small tactical asks. One afternoon in April, I emailed Rebecca asking if Brian could stay for lunch and recess on Wednesdays to join a walking group at recess — a structured activity with fewer opportunities for him to get in trouble than free play. A stepping stone, not a full reintegration. Most of the items below started as small asks like that — quiet experiments that worked, formalized into the document the school could file.

Recess was its own problem. A few weeks after the walking group started, Brian tried to join the basketball game on a regular recess day and was told he was a bad player; he walked to the kickball game and was told to go away. By the time I picked him up, he was crying. By the time I got home, I had a five-day plan: walking group Wednesdays, indoor board games with hand-picked classmates Monday, Thursday, and Friday, and Tuesdays out altogether. I told the school I'd provide the board games myself. Sometimes the laundry list grows by one item at a time. Sometimes it grows in an afternoon, because your kid came home crying.

> *I'm really proud of Brian for not cussing out the kid(s) who wouldn't play with him or let him play.*
>
> — From an April 2008 email to Brian's elementary school teacher

* * *

Daily Structure

- At the beginning of each day, Brian needs to process his day with a consistent person trained in behavior management strategies. At this time, Brian will review his behavioral and academic expectations and plan for what he is going to do that day.
- Brian needs to be reminded to focus on what he needs to do each morning.
- At the end of each day, Brian will review what he has done throughout the day with the same consistent person and discuss any accomplishments or improvements he needs to make for the following school day.

Social and Emotional Supports

- Weekly social skills group with the school counselor or school psychologist to develop and practice appropriate social interaction skills and better understand the social constructs of a school environment.
- Individual meetings with a counselor or psychologist to develop understanding of social cues, the effect of his behavior on others, and coping strategies for when he becomes upset or frustrated.
- Access to a trusted individual and a chance to debrief with a safe, consistent person.

Academic and Organizational Supports

- Organizational assistance to help Brian keep track of, write down, and hand in assignments and homework.
- Use of wide-ruled lined paper for writing.
- Ability to type longer assignments.
- Teacher monitoring of his agenda book.
- Verbal discussion of what he is going to write before he writes it, to aid with organization.
- Teacher prompting and encouragement to extend his responses.

Staff and Environment

- Training for staff members on Brian's behavior plan to ensure consistency.
- Close adult supervision for safety and behavior management during arrival, class time, dismissal, transitions, lunch, and recess.

Placement Note

Brian is a very bright, motivated student who needs the academic stimulation of a general education environment, and additionally needs support.

Between the Letters: Evan's Quieter Asks

Brian's school life generated formal documents. Evan's school life generated emails like this one.

In late April 2008, Evan came home from kindergarten with his lunch barely touched. When I asked him why, he told me the cafeteria really smelled bad and he couldn't eat. Brian, age 11 and an authority on the cafeteria, confirmed: it was more stinky than usual that day.

The problem wasn't the smell. The problem was that Evan hadn't said anything to anyone about the smell. He hadn't asked his teacher, Mrs. Cleggett, if he could eat somewhere else. He hadn't told the lunch monitor he wasn't feeling well. He hadn't done any of the things a child is supposed to do when a thing is wrong. He just sat with his lunch and didn't eat.

So I ran a scene with him in the kitchen. Evan played Mrs. Cleggett. I played Evan. Brian played Evan's friend Paul. I raised my hand and said: Mrs. Cleggett, the cafeteria is too smelly today. Could I please eat somewhere else? Evan watched, processed, and seemed to get it.

But I knew it wouldn't stick from one rehearsal. So I emailed Evan's kindergarten teacher Kendra and asked her — and Mrs. Cleggett — to walk him through it again. Then I added the part I always added:

> *Maybe something else to discuss in his IEP? Not sure how to target that goal. Do you have any ideas?*

Brian's advocacy was loud because his needs were loud. Evan's advocacy had to be just as deliberate, but quieter — because his needs were quieter. He didn't melt down. He didn't shove the teacher. He just stopped eating, and didn't ask for help, and would have kept not asking until somebody noticed.

The trick with Evan was always noticing first.

A Postcard from September 2008

Middle school started on September 2nd. By 8:14 a.m. that morning, I was already emailing Brian's new case manager.

Brian couldn't fit his binder in his backpack. He was carrying a tote bag instead, plus a lunch box, plus an algebra book, and could barely manage the load to the front door. He has low muscle tone — he's been hypotonic since he was a toddler — but he wouldn't consider a rolling backpack because he didn't want to stand out.

We had spent hours over the summer getting him organized for the year. We had picked the velcro binder specifically so things wouldn't slide out and get lost. None of it had survived the first morning.

I closed the email like this:

> *As we don't "go with the flow" very well, any suggestions would be great.*

I didn't yet know that the "we" was more accurate than I meant it to be. I thought I was describing Brian and my family's general personality. I was actually describing four autistic people who would eventually all be diagnosed, including me. We genuinely didn't go with the flow. We weren't built to.

I would not figure that out for another fifteen years.

Between the Letters: March 26, 2009

On March 25, 2009, Brian had an incident at school. He was dysregulated and overwhelmed, and he became physically aggressive toward a staff member. Staff restrained him to prevent further harm. He was 12 years old. He had been working with the team at Harper's Choice Middle School all year, and the team — Amy the school psychologist, Rebecca the special educator, the case manager — knew Brian well. None of them wanted what happened that morning to happen. But it happened.

This entry isn't about the incident itself. It's about what happened the morning after, which is the part that matters most for advocacy purposes.

Two emails arrived in my inbox within sixteen minutes of each other. One was from Amy, the school psychologist, who had been part of restraining him. She wrote:

> *I, myself, was and am very sad about what happened yesterday. It always "hurts" me to have to restrain a child, and its worse when I have a close relationship with that child. Seeing Brian really struggling (physically and emotionally) was difficult. I have already begun the process to involve the behavior specialist… I am committed to helping Brian, and you.*

That is what a school psychologist who is on your team sounds like the day after she had to put her hands on your kid. She wasn't deflecting. She wasn't covering. She was telling me, plainly, that it had hurt her too. Then she asked a real question — should we revisit the incident with Brian even though he typically considers it closed once he calms down? Was the family's accommodation of his "incident is over" wiring helping him or shielding him from the chance to learn? She compared it, gently, to her own daughter's eating habits. She was thinking out loud with me as a partner.

Sixteen minutes later, the second email came in. This one was from the administrator running the discipline process. It was crisp and procedural:

> *Due to the severity of the incident Brian has been suspended for at least four days (until we have the meeting on Tuesday). We will meet on Tuesday for a manifestation meeting to determine if this behavior was manifested in his disability.*

A manifestation meeting is what happens under federal disability law when a school wants to discipline a kid with an IEP for more than ten days: the team has to determine whether the behavior was caused by, or had a direct and substantial relationship to, the child's disability. If it was, the discipline can't proceed the way it would for any other student.

I emailed back the same day:

> *Could we meet before Tuesday? If not, why so long between the incident and the resultant consequence? We all know that with Brian, he barely (if ever) connects a consequence with a past behavior, but there's practically no chance that connection will occur when the consequence is imposed six days after the behavior. In Brian's world, he was "upset and depressed", acted inappropriately, apologized, and it's all over in his mind. The longer we wait to talk to him and make decisions, the less effective they may be.*

I was making the school's argument back to the school. Here is what your consequence is supposed to accomplish. Here is why your timeline defeats the purpose. I wasn't trying to get Brian out of trouble. I was trying to get the school to apply its own logic.

The disability attestation letter that comes later in this document — the strong one, the one I wrote and asked the psychiatrist to sign — came less than a year after this incident. The deliberate emphasis on Brian's worst days, the things I leaned hard into to qualify him for what he needed, came from a parent who had already seen her son restrained at school, suspended, and processed through a federal disability law procedure to determine whether his autism counted as a defense against his own school. The strong language was the lock. The disability attestation was the key.

A Word About Pushing Back

A month after the restraint and the manifestation meeting, Emily Newland, the special education teacher coordinating Brian's case, wrote me a warm, well-coordinated email about Brian's 4th-quarter related arts schedule. He'd be taking FLEX (a study skills class) and Art. Both teachers had been briefed. Both had agreed to accommodate Brian. The team felt confident he'd have a positive experience with the proper supports.

I wrote back the same day:

> *Not to be contentious, but I disagree. You can't take a "boring" subject (to Brian) with a teacher whom I've heard from other parents is not very dynamic, and make it all work out with positive reinforcement. If "positive reinforcement" in the face of a non-preferred or distasteful activity made any significant difference on Brian, his behavior would have changed long ago. In other words, he would have learned to go with the flow to a certain extent because there have been many, many times that I and others have tried positive reinforcement. He hasn't, and he doesn't.*
>
> *If you would like to experiment with Brian and 4thQ Related Arts, give it a whirl. I am keeping my opinions to myself around Brian, and he doesn't know what I'm thinking. I'm sure he'll do his best as he always does, but if you add up 1) the end of the day, 2) a boring class, and 3) a trigger tbd, it's not a great mix. He'll be using all of his coping skills to stay in the chair and to try to stay focused. He won't have much left. Sounds like we're setting him up to fail.*
>
> *BTW, he came home today saying that Ms. Allero was nice, but that FLEX was boring.*

That's the email of a parent who had stopped being optional in school planning conversations. I wasn't being a problem. I was being a data set the team didn't have. Brian had eleven years of failed positive reinforcement attempts behind him by April 2009, and I had been there for every one of them. The team had a kid in front of them for one quarter. I had the longitudinal study.

Sometimes the school is doing everything right and still planning something that won't work. The teachers have been briefed. The accommodations are written. The case manager is being thoughtful. And the plan is still wrong, because the plan was built from the school's data and you have data the school does not. Push back anyway. Politely. With evidence. With a BTW at the end if you can manage it.

A week later, Emily emailed me back. She'd been in a room with Amy and the case manager. They had heard the pushback. The 4th-quarter Art placement was off the table. Instead, they

had built a custom 90-minute schedule for the block I'd called the recipe for failure: forty-five minutes in Emily's classroom with a trusted aide working on homework, logic puzzles, or board games — Brian's choice; then forty-five minutes as an office aide, filing mail into teacher mailboxes, because the office staff knew Brian well and had volunteered to have him help out. That's not a schedule. That's a care plan. This is what pushing back is supposed to produce. Not a fight. Not a paper trail. A better plan, built by people who took the data seriously and went back to the drawing board with it.

Here We Go Again

By August 2009, I had developed a habit. Before any school year started for either kid, I emailed the case manager.

For Brian, those emails were typically a paragraph or two of warnings I'd already given the team verbally — repeated in writing, so they were on the record. For Evan, the August emails were a different animal. Evan didn't generate his own incident reports. If something was wrong, Evan went quiet. The case manager would never know what hit him because Evan wouldn't tell her.

So I told her instead. On August 24, 2009, eight days before the start of first grade, I sat down and wrote out everything Evan's new teacher needed to know that the IEP wouldn't say:

> *Evan is nervous and expressing concern that his new teacher be aware of his fear of fire alarms, fire drills, alarms of any sort, blank tv screens, computers shutting down, printers, bathrooms, dogs... I could go on, but those are the main ones he might see at school.*

Then the example that mattered most. The weekend before I wrote this email, Evan had been diagnosed with strep throat. He had spent Saturday night lying awake in his bed, with a fever, in pain, waiting for the fever to go away. He hadn't come to find me. He hadn't asked for Advil or water. I only found out on Sunday morning when I asked him directly — and his throat, by then, was inflamed and red enough that the diagnosis was immediate.

So I told the case manager that, too:

> *He needs an eye on him, not just academically, but to gauge from his behavior how he's doing. Someone who will remind him that he doesn't have to wear his coat if he's not cold (and that he needs to speak up for himself). And that if he's confused, or not feeling well, to speak up.*

I closed the email with the line that was, by 2009, the closest thing I had to a thesis statement about Evan's school day:

> *If he's fearfully awaiting a fire drill to go off, he will not absorb academically.*

The IEP would handle math, reading, and goals. The IEP would not handle dogs on leashes, sensitive printers, or a ten-year-old lying in the dark waiting for a fever to break because asking for help wasn't part of his wiring. That was on me to handle. I handled it by writing it down and sending it before school started, so nobody had to find out the hard way.

If Brian's advocacy was about teaching the school to read his behavior correctly when it got loud, Evan's was about teaching the school to read his behavior at all — because his behavior, when something was wrong, was almost imperceptible.

A Different Kind of Letter

By the start of the 2009–2010 school year, we'd made the call. Brian was coming out of public school. Again.

He'd done 6th grade in public school the year before — which is the year that produced the restraint, the manifestation meeting, the pushback, and the redesigned schedule covered in the preceding sections. The team at his school had done good work. Brian had still come home crying more than he should have. By August, Ed and I had decided that homeschool was the best placement for 7th grade. We'd homeschooled before. We knew what it took. We also knew that none of the formal advocacy in the world would replace what Brian actually needed, which was a year of breathing.

So I wrote a different kind of letter. This one wasn't to a doctor, a principal, a case manager, or a school psychologist. It was an introduction email to a homeschool group:

> *Hi everybody, I wanted to introduce ourselves. I'm Cyn Snow, and I'm homeschooling my son, Brian (12 yo). We have homeschooled before, but we took last year off and opted for 6th grade public school. This year, we've decided that homeschool is the best placement. Brian's brother, Evan, is in 4th grade in public school.*
>
> *Brian has Asperger's and is very smart! He would love to make some new friends that share his interests. Brian's biggest passions are college football, and Wii games. He wants to write a crime/suspense novel, and also to be an actor one day. We hope to meet some of y'all who might share these interests.*
>
> *We're excited to join your group!*

I want you to notice what's not in this letter.

There are no diagnoses framed as deficits. No mention of the restraint. No mention of the manifestation meeting. No accommodations list. No clinical language. No request for understanding. Just a kid who likes college football and Wii games and wants to write a crime novel and act in plays, and a mom who hoped some other kid in this homeschool group also liked those things.

That's the other side of advocacy — the part that isn't writing letters or pushing back or filing IEPs. The part where you go find your kid a friend. A community. A room where his diagnosis isn't the first thing anyone learns about him. Where what they learn first is that he wants to write a crime/suspense novel, and they get to find out he has Asperger's later, the way you find out anyone's anything — slowly, as you get to know them.

Sometimes the most important advocacy letter you write is the one where you don't advocate for anything. You just introduce your kid as a kid.

A Goodbye Letter

Six days after the start of homeschool, I wrote a second letter. This one was to the public school team we had just left.

I told them Brian was settling into a routine. I told them about the Y's drop-in PE classes for homeschoolers, and that Aidan — Brian's best friend — was signing up too. I told them about the library books on algebra and the field trips in the works. I told them we thought we'd made the right call.

Then I told them what I'd carried out with me.

> *I've always believed that there's a reason for everything and that there is a big picture in which each of us plays a part… I took a Spiritual Gifts Inventory at church several years ago, and was assessed as having the gift of "suffering." I don't remember exactly what that means, but I often think that through our family's fairly unique set of circumstances, "suffering" is just part of who we are. I hope I don't sound narcissistic — certainly don't mean it that way! We're certainly not a big hairy deal. But as a rule we Snows don't go through this world quietly. We tend to leave an impact.*

Then I named the thing I had been carrying since the March incident.

> *I especially hope that Ms. Trainer is doing well. I couldn't begin to tell her how sorry I feel for what happened, and pray she's OK.*

Ms. Trainer was the staff member Brian hurt in March. I had not, at any point during the discipline process or the manifestation meeting, had a direct chance to say what I wanted to say to her. The institutional documentation kept the focus on Brian's disability, his accommodations, and what would happen to him next. The whole formal apparatus was about Brian. Ms. Trainer was not in those meetings.

So I tucked the apology into the third-to-last paragraph of my goodbye email and hoped someone would pass it along. I don't know if anyone did. One of the hardest parts of advocating for a kid who occasionally hurts other people: you spend most of your energy defending him from a system that wants to discipline him for symptoms of his disability, and you can run out of energy before you get to the person he hurt. That is not okay. It is also what happened. The apology has never been Brian's to make. He was a dysregulated 12-year-old in a meltdown. The apology was mine. It was the kind of apology a parent owes the person their kid hurt, regardless of whether the kid is neurotypical or autistic, regardless of whether the hurt was intentional or symptomatic. It still applies. I am still sorry.

I closed the email with what was left, which was gratitude:

> *Each of y'all had a positive impact on our lives for which I'll be eternally grateful. So thank you, thank you.*

The homeschool intro letter was a hello. This one was a goodbye. Both were sent in the same week. That's what leaving a school system actually felt like — a hello sent forward, a goodbye sent backward, and a name I would carry with me for the next sixteen years.

Warm Handoff

In late November 2009, three months into Brian's homeschool year and Evan's first-grade year at Swansfield, we found out we were moving again.

Not far. From Howard County to Stevensville, on Kent Island — a slower, more rural part of Maryland that Ed and I thought might be better for the boys. It was the family's second relocation in fifteen months. Brian had handled the first one (Georgia to Maryland) about as well as you'd expect, which is to say poorly. Evan had handled it about as well as you'd expect, which is to say invisibly.

Evan would be starting at the new elementary school in January. I wrote to his Swansfield team in late November and asked them for one thing the formal records transfer would not provide:

> *As we discussed at teacher conference last week, it would probably be very helpful for Evan's transition if educator-to-educator, you might call ahead and say a little about Evan from your perspective.*

A warm handoff. A phone call between two professionals about a kid one of them had never met. The kind of thing that doesn't show up in any file, and that the receiving school would never know to wish for unless somebody asked.

I also asked something else, which Evan's wiring made non-negotiable:

> *We are going to Stevensville this Friday for the home inspection, and my hope is to take Evan along, and arrange a tour of the school so that he has some idea of what's to come.*

For Evan, the threat was never the destination. It was the unfamiliar. Every accommodation we'd built into his Swansfield school day — the bathroom with no auto-flush, the advance warning before fire drills, the teacher who knew his triggers — was about to evaporate. The new school's adults didn't know him. They didn't know what he didn't ask for help with. They didn't know about strep throat lying awake in the dark.

So we pre-visited. We toured the school. We met the people. We did the work of making the unfamiliar familiar before the actual transition arrived. None of it was in an IEP. None of it would have happened by default.

I closed the email with the line that captured what the Swansfield team had been to us:

> *I don't want to call the school and just drop everything on them (like we did with you guys). :-)*

Translation: I know we were a lot. Thank you for being a lot back.

If Brian's advocacy was loud, and Evan's was quiet, the transition advocacy for Evan was both at once — loud in the asks, quiet in the way the asks were designed to land. Make a phone call. Let us tour the building. Don't make him walk in cold. None of it dramatic. All of it essential.

Disability Attestation Letter

February 1, 2010

Another example of advocacy writing — this one I drafted myself and had Brian's psychiatrist, Brett Greenburg at The Adolescent Clinic, sign.

A note before the letter itself: I leaned hard into Brian's challenges on purpose. The point of this letter wasn't to capture who Brian is — it was to qualify him for what he needed. Every sentence was calibrated to sway the outcome. I wouldn't describe Brian this way in any ordinary conversation, and Brian, if you're reading this — forgive me. It sounds rough because it had to. I wasn't writing about my son. I was writing a key that fit a specific lock.

* * *

This document is to attest that in my opinion, Brian Snow is "permanently and totally disabled" under the following criteria:

- Brian's diagnoses include Asperger's Disorder, Attention Hyperactivity Disorder, Non-Verbal Learning Disability, Depression, Anxiety, and Sensory Integration Dysfunction.
- Brian has low endurance due in part to a history of hypotonia/low muscle tone.
- Brian's conditions have severely and negatively impacted his ability to perform typical tasks of childhood — e.g., attend school, participate in organized sports or camps, or develop and maintain friendships.
- Brian has a history of impulsivity and loss of self-control that limits his ability to participate in typical societal activities.
- Brian has a history of being unsuccessful in maintaining functional relationships with peers and teachers at school. Brian has been suspended or expelled from several schools.
- Brian has a history of becoming overwhelmed and losing self-control. When this occurs, he may lash out physically or elope (fight or flight). This has resulted in the authorities/police being notified on multiple occasions. Brian was also hospitalized on one occasion, restrained to a gurney, and tranquilized. Brian's parents report that they have had to restrain Brian on multiple occasions, dating back to the time he was a toddler.
- Brian's sensory profile is significant. He is unable to sit or stand for prolonged periods, which negatively impacts his ability to perform typical activities.

Medications have helped Brian somewhat but have been unable to alleviate the majority of these symptoms and impairments.

These symptoms are not expected to dissipate at any significant rate, and they have manifested since the time Brian was in Kindergarten.

Signed: Brett Greenburg, MSA — The Adolescent Clinic

Two Family Trip Letters

The next documents are two letters Ed signed on the same day in December 2010 — one for Brian's middle school, one for Evan's elementary school. The trip was the same: Ed's work conference in Orlando. The schools were different. Formal address to both principals. Proposed projects. Warmest regards, Ed Snow.

Ten months earlier, I had written a letter just like it — for Evan, asking his new school in Stevensville to excuse him for four days while we visited Atlanta. The advocacy move was identical. The tone was completely different.

> *Hi Doreen (is it OK if I call you Doreen)? One of my best friends from Atlanta is a Doreen.*
>
> *Evan was born in Atlanta, and we lived in Atlanta until he was eight. We have many friends there and miss everyone a bunch. As it turns out, my husband has a business trip to Atlanta scheduled, and frequent flyer miles sufficient enough to bring the family with him. Evan would miss four days of school while we are away, but it's a tremendous learning and life experience opportunity for him. Evan loves to travel and loves to fly… it's like his brain comes alive whenever we travel.*

Doreen wrote back the next afternoon:

> *Of course, please call me Doreen. I prefer it. There aren't too many of us around… The trip will be no problem. Just send a letter to Mr. Rafton as soon as possible and he will forward it to the office. It will be an excused absence. Actually it is technically considered a family vacation.*

That's what happens when the warm handoff worked. Six weeks into Evan's transition to the new school, his guidance counselor was on a first-name basis with me, telling me about the other Doreen O'Conner she'd found on Facebook, and approving a four-day absence to Atlanta over the course of two sentences.

The Orlando letter that comes next was written to a school that did not know us. It was formal because it had to be. The Atlanta exchange happened in a school that already knew Evan was the kind of kid who comes alive on an airplane and would benefit from a few days back where he started.

Both letters got approved. Both trips happened. The difference between them — between Hi Doreen and Dear Mrs. Wilhelmi — is the entire payoff of all the relationship-building advocacy in the section opener. Be in the building. Thank the people who show up. By February 2010,

Doreen O'Conner was a person who showed up for Evan, and I was a parent who had introduced myself by first name on the second email.

Letter to the Middle School Principal

December 7, 2010

A different kind of advocacy letter. The others were asking schools to step up — provide accommodations, evaluate, place, modify. This one was asking the school to step aside.

Ed had a work conference in Orlando, Brian's birthday fell during the trip, and I was working through the holiday rush at Southwest, which meant family time was scarce. So Ed signed this one — it played better coming from the dad, and the proposed research project gave the principal a clean justification to say yes. Advocacy isn't always about asking for more. Sometimes it's about asking for a different kind of more.

* * *

Dear Mrs. Wilhelmi,

We would like to share with you that Brian has a wonderful opportunity to travel with his mom and me as I attend a work conference in Orlando, Florida from December 13–17, 2010. This travel opportunity is especially valuable since Brian does not take social studies in school — so this actually comprises a week-long social studies field trip! He is a hands-on learner and truly soaks in each travel experience.

Additionally, my wife Cyn works for Southwest Airlines and she is at her busiest over the holidays when families are traveling. We realize how important school attendance is; however, the Snow family time over the holidays will be very limited.

We propose that Brian be excused for these days. Given the opportunity, he will do a research project on Orlando — internet research as well as hands-on investigation — and put together a presentation to bring back to school. Topics may include Orlando's major industries, famous people from Orlando, local food favorites, transportation, etc. Or if you have a different project area in mind, we would be delighted to hear it as well.

Brian will celebrate his 14th birthday while in Orlando and he is thrilled at the prospect. It's a great opportunity for him.

Again, we truly understand that school attendance is important. We thank you in advance for your understanding and support of our family time and for Brian to experience this hands-on learning.

Warmest regards,

Ed Snow

Letter to the Elementary School Principal

December 7, 2010

Ed signed a second letter the same day. Same trip, same conference, same proposal — but for Evan, addressed to the principal at his elementary school. We sent both letters on December 7, 2010, an hour apart. Same playbook, two recipients, two schools, two grade levels.

* * *

Dear Mr. Dunne,

We would like to share with you that Evan has a wonderful opportunity to travel with his mom and me as I attend a work conference in Orlando, Florida, December 13–17. As you may have heard from Mrs. O'Conner or Mrs. Hartley, Evan "comes alive" when he has the opportunity to travel. He is a hands-on learner and truly soaks in each travel experience.

Additionally, my wife, Cyn, works for Southwest Airlines, and she is at her busiest over the holidays when families are traveling. We realize how important school attendance is; however, Snow family time over the holidays will be very limited.

We propose that Evan be excused these days given that he will do a "video journal" project to bring back to school from the learning opportunities he'll experience in Orlando. Traditionally, Evan's video journals allow him to share his excitement and what he has learned about the city we visit, as well as his knowledge of airports, hotels, and ground transportation. Each trip provides an excellent educational experience for Evan, and he is never so chatty as he is in a video journal. For a kid with autism, being "chatty" in an appropriate fashion is impressive.

Also, Evan will turn in his simple machine project this Friday (the 10th) so that he has it in ahead of the 12/15 due date.

Again, we truly understand that school attendance is important. We thank you in advance for your understanding and support of our family time and for Evan in his unique learning style.

Warmest regards,

Ed Snow

Things Get Quieter

By August 2010, Evan was starting second grade at Matapeake. The warm handoff had worked. So had the school tour the previous December. So had the introductions to a new community. The advocacy work was no longer about transitions or crises. It was about water bottles.

> *After school, he made a beeline straight to the faucet and drank two glasses of water. When I checked his lunchbox… he hadn't drunk his snack juice box (said he didn't know it was there and didn't see it). He didn't drink much of his water bottle that I sent either. And of course, he doesn't care much for water fountains, and said he didn't drink there either.*
>
> *As hot as it is this week, and I hate to bother you with something else cuz I know you've got a full plate, but would you check with him from time to time, just to remind him to get a drink.*
>
> *P.S. I hear there's a fire drill today. Chances are that the fire drill will be Evan's primary focus until it's over. Stephen and Kristen Ellison found last year that it was generally a good idea to not tell Evan in advance about fire drills cuz he obsesses about them. Kristen would just show up a few minutes in advance and escort Evan out and that worked well. Just my two cents.*

Ms. Peggi wrote back five sentences:

> *I'll remind him to drink during the day. And yes, we will tell him prior to the drill and we practiced yesterday with Mrs. Besch. He's a great kid!*

What I want to point out about this exchange is what it isn't. It isn't an IEP meeting. It isn't a manifestation review. It isn't a doctor-signed letter. It isn't a placement request. It is a parent and a teacher, on a first-name basis, trading practical observations about how to keep a kid hydrated and how to handle a fire drill in a building that has them often.

The previous year's teachers — Stephen and Kristen — were referenced casually, by first name, with their accumulated knowledge of Evan handed off across school years without anyone calling it a handoff.

The September 2008 postcard at the beginning of this section was Brian's first day of middle school in Howard County — an emergency by 8:14 a.m. Two years later, this is what Evan's first week of school looked like: a water bottle question and an updated fire drill recommendation. The advocacy infrastructure was working. The relationships were doing the heavy lifting. The emails were getting shorter.

That's what every autism family is working toward, whether they know it or not. Not the absence of advocacy — that doesn't exist — but advocacy that gets boring. That fits in a single email. That ends with He's a great kid! and an exclamation point.

By 2010, we had figured out how to be quiet — at least for stretches at a time. The relationships did the work. The systems held. The emails got shorter.

It did not last in any total way. Brian returned to public school for 8th grade in fall 2010 at Centreville Middle in Queen Anne's County. Evan continued at Matapeake. There were more emails, more incidents, more adults to meet, more handoffs, more buses, more spring breaks. The advocacy did not stop. It just stopped generating the kinds of high-stakes documents the first part of this section is full of.

The pattern, by then, was visible: the system worked when the right adult was in the right room. Not the IEP, not the accommodations document, not even the diagnosis. The variable was always whether Brian or Evan had landed in a classroom run by a Rebecca Bell or an Amy McMillan or someone like them — one of the adults who saw a kid where another adult would have seen a problem. We were lucky enough, over the years, to find several. The next few pages collect a handful of brief moments from the years that followed, before the section picks up again in adulthood. I am grateful to every adult in them.

A Word About Recovery

Pushing back is a real skill. So is recovering when the school pushes back at you.

In September 2012, two weeks into Brian's 10th-grade year, I emailed his technology teacher about an incident. Brian had wanted to play Spider Solitaire on a classroom computer during what he perceived as down time. A groupmate told him to get off. The groupmate shoved him. Brian wrote a sticky note that said Seth shoved me, stuck it on the teacher's shirt on the way out of class, and went home. The teacher — who hadn't seen the shove — assumed Brian was being playful, said “nice try, Brian,” and threw the note away.

Brian came home and told me. I emailed the teacher that evening. The email was the email I always wrote — factual sequence, reasonable hypothesis (I suspect you were unaware of what happened and may have misunderstood), diagnostic observations, concrete suggestions, and reminders that Brian had support tools available. The kind of email I'd written a hundred times by then.

The teacher wrote back early the next morning. His reply was reasonable on the facts. Then, in the last paragraph, he pushed back on me directly:

> *I believe your statement that there is a significant amount of unstructured time in the class is unfounded and incorrect. I take a great deal of pride in taking a large group of students and giving them a good lesson everyday within a well structured environment. You are welcome to come visit my class any day you like to see first hand how my class is conducted. Perhaps then you will have a different opinion, or rather an informed opinion.*

He had been cc'd with the special educator, the case manager, his department chair, and Ed. I had embarrassed him in front of four people. He pushed back.

I wrote back within an hour. The opening: I apologize if I overspoke about the “unstructured” classroom time, and I'm sure that for most students your class is wonderful. Then I shifted the framing — same data, different frame: Brian however, reports a lot of down time. Not your class has too much down time. Brian's experience. Then a soft cite of the formal record: He doesn't do groups well, and that's why we've had it in his IEP in the past. Then partial responsibility for the friction: It's a learning curve that we all go through every time Brian has a new class or a new teacher. We'll get there! Then warm close, exclamation points. The kind of email a teacher can read at the start of his next planning period and not flinch at.

Mr. Coynor replied at noon. He had moved Brian into a group of all girls. He had prepped the girls beforehand. He had prompted Brian to interact. He had coordinated turn-taking on the video editing. He had told Brian to come to him directly if there was an issue. At the bottom of his email, he added a postscript:

> *p.s. for what its worth I have lots of ideas that others tend to ignore :)*

He was telling me he understood Brian. He had, sideways, said I'm like that too.

I wrote back the same afternoon:

> *Sometimes it just takes the right person or combination of people to unlock the treasure that is Brian. I guess I'm biased. :-}*

That was the full arc. Twenty-four hours. Four emails. One teacher who had pushed back hard and one parent who had recovered well. Brian got a workable group of girls. Mr. Coynor became one of the adults in Brian's life that year who was actually paying attention.

Recovery is not capitulation. It is not retreat. It is the work you do after you push back to keep the relationship intact — because the relationship is the whole point, and the teacher you are recovering with is going to be in the room with your kid five days a week until June.

A Few More From the School Years

Compact entries — small advocacy moments from the years between Things Get Quieter and the adult section that follows. Each one shows a different version of the same pattern.

* * *

February 2011 — Brian, Centreville Middle, 8th grade

Brian had a rough morning on the bus. Another student, Caleb, was screaming. Brian told him to shut up. Then Brian gave him the middle finger. The bus aide texted me about it before homeroom.

I replied to the school the same morning with the line I'd been saying for a decade: If Caleb screams, Brian can't handle it. Not gonna change. The low frustration tolerance, the anxiety, the sensory defensiveness — Asperger's, in three nouns. The cycle wasn't going to break by punishing Brian for reacting to a trigger that wasn't going anywhere.

The next day, Brian's special educator, Rebecca Clarke, wrote me a full report on how the rest of the morning had gone. She'd talked Brian through the bus incident in homeroom. She hadn't dwelt on his foul language. She'd asked him what he wanted to do, including the option of not going to class first thing if he needed more time to decompress. He chose to go to class. He completed his current events paper. By language arts, he was presenting in a small group in front of his peers.

I wrote back:

> *You have fulfilled the role of the onsite "psychologist," very similar to Amy McMillan at Harper's Choice Middle in 6th grade. And she is actually a psychologist. I wonder who will possibly be as wonderful as you next year? It's a really tough role to fill. But imperative to Brian's success that we do so.*

Becky Clarke had become the next adult in the lineage.

* * *

August 2012 — Two emails, twenty-two minutes apart

Brian was starting 10th grade at the high school main campus. Evan was starting 7th grade and moving up to middle school. Both kids were transitioning. I emailed each school in succession on August 6, twenty-two minutes apart, before we left for a ten-day trip.

To Brian's high school case manager, the checklist included: Where will Brian eat lunch? Was the bean bag from the Annex moved to the Main Campus? Where would Brian go if he needed to

use his Chill Pass? Last year Nikki and her friend Michelle ate lunch with Brian most of 2d semester — do their lunch schedules coordinate this year?

The bean bag was the same bean bag Brian's elementary school had set up for him years earlier. The accommodation that worked best was the one he never used. Several years and several schools later, it was still traveling with him.

To Evan's middle school case manager, twenty-two minutes later: Is the “therapy bathroom” (that's what Evan calls it) still available? Will he be able to change for PE in the therapy bathroom? Are the ball chairs inflated and available in each classroom? Of course he is concerned that he be taken outside prior to every fire drill. Pickup at the same spot in front of the house as last year.

By 2012, this was the rhythm. Two kids, two schools, two emails, one mom, one trip, two checklists. The infrastructure traveled with them. So did I.

* * *

May 2014 — Evan, 8th grade, the wrong bathroom

Evan had a tornado drill at school. His class's designated safe place was a bathroom — but not his bathroom. This bathroom had hand dryers. As we'd been telling Evan's teachers since first grade, being near hand dryers was, for Evan, terrifying.

He came home and told us about it. The next morning at 7:53 a.m., I emailed the SPED instructional specialist:

> *In the event of an actual emergency, he understands that he would have to go into the nearest “safe place.” But for drills, he requests being able to go elsewhere, for example the therapy bathroom (“his” bathroom).*

Katie wrote back by 1:00 p.m. She apologized. She'd been at a BOE meeting when the drill happened. She arranged an alternate location for future drills. She offered the hallway with another class as a backup. She would remind the teachers.

> *I do hope he was ok and didn't have alot of stress about it at home last night. I will fix it so that it won't happen in the future.*

Six years after Evan first identified the therapy bathroom as his, by name, the accommodation was still in operation and still being adjusted in real time when the system slipped. The right adult was in the right room, again. The infrastructure traveled.

* * *

March 2015 — Evan, 9th grade, Spanish field trip

Evan was going on a Spanish field trip to Towson with his 9th-grade class. I emailed his Spanish teacher and asked if I could chaperone, the same way I'd been chaperoning field trips since elementary school.

Rob Glaser wrote back the same afternoon:

> *I would certainly love to have you as a chaperone. For every 15 students that are going on the field trip I can have one extra adult whose ticket is free! I am going to take interest on a first come first serve basis, so you are first on my list! I have factored in the costs of the bus and tip for the chaperones into student cost, so do not worry about extra payment. Thank you so much! Evan is one of my biggest participators and I'm glad to have him in class.*

I want to point out what this email isn't.

It isn't an accommodation request. It isn't a disclosure of Evan's diagnosis. It isn't a warning about fire drills or hand dryers or therapy bathrooms. It isn't a request that the teacher pre-meet with Evan, or that the bus be configured a particular way, or that Evan be excused from anything. It's a chaperone offer and a yes.

By 9th grade, Evan's teacher described him as one of my biggest participators. Six years earlier I'd been writing his kindergarten teacher about strep throat in the dark. Now a Spanish teacher who'd had Evan in class was saying he was glad to have him.

That's where this section's childhood years end. Not at a milestone, not at a graduation, not at a diagnosis update. At a Spanish field trip to Towson, an offered ticket, and a teacher who liked having my kid in his room.

* * *

By the time the next document was written, both boys were grown. Brian was an adult living near Annapolis. Evan was an adult starting a federal career. The advocacy work had continued through every year between this page and the next, but the documents had largely moved into emails, phone calls, and IEP meetings that didn't generate paper I held onto. The next letter in this section is the one I wrote, for the first time, for myself.

ADA Accommodation Request — Cyn

2023

This one was for me. By 2023, I'd been writing advocacy letters for over twenty years — for Brian, for Evan, and occasionally for Ed. I knew the template. I knew the language. I knew which symptoms to name plainly and which functional impacts to spell out so a reviewer couldn't miss them.

So I did what I'd always done: I wrote the letter myself and asked the clinician to sign it. Same playbook I used for Brian's 2010 disability attestation, just turned inward. What was strange was the byline. Every letter I'd ever written started with someone else's name. This one started with mine. I'd spent two decades translating my kids' nervous systems into administrative language. It turned out I'd been preparing to do the same thing for my own.

* * *

This letter is written on behalf of Cyn Snow, who works at the Department of Commerce.

Cyn's medical impairments include focus and attention issues, severe anxiety, and Autism Spectrum Disorder.

Focus and Attention

Her brain chemistry, focus, ability to attend, and particularly anxiety have all changed since the pandemic. Cyn became conditioned to “no distractions” and a stable sensory environment during the long time spent working alone at home. Since the requirement to return once weekly to the office, she is easily and frequently distracted. It often takes the first couple of hours of a workday for her to get cognitively and spatially organized to begin working. When Cyn is required to work in the office, it often means many wasted work hours.

Anxiety

Cyn suffers from clinically significant levels of health anxiety, and the level of anxiety has greatly increased since the return to work post-pandemic.

Anxiety manifests in Cyn as increased heart rate, breathing issues, nervous energy, difficulty concentrating, headaches, irritability, gastrointestinal issues, and inability to focus.

Driving — and especially driving in heavy traffic — is a frequent trigger of her excessive anxiety.

Cyn became conditioned to a steady, distraction-free pace while working at home during the pandemic. Since returning to the office, her anxiety has steadily increased, which is negatively impacting her mental and physical health.

She struggles daily with severe, anxiety-related sleep issues. She never sleeps through the night, and typically wakes up between 3 and 5 times each night. On the nights when she has to drive into the office the next day, she is frequently so anxious about the traffic and the drive that she gets up in the middle of the night and drives in to work. With her astigmatism, driving in the dark is not recommended for Cyn — it becomes another exacerbator of her anxiety.

Autism Spectrum Disorder

Routinization set in with the pandemic — restricted or repetitive behaviors, interests, and activities, including sensory processing difficulties. Cyn became settled into a home-based routine that fits her sensory profile, including reduced lighting and sounds and increased ventilation (lowered temperatures). Since returning to office, Cyn has struggled with hot flashes and the inability to keep the temperature at cooler levels.

Cyn suffers from visual-spatial processing disorder, which has worsened with age. This impacts her comfort level and anxiety while driving in high-traffic areas.

While autism itself doesn't necessarily get “worse” over time, stress can make existing symptoms more pronounced and affect the overall well-being of someone with autism. Stress can lead to increased sensory sensitivities and irritability. In Cyn's case, she becomes easily overwhelmed.

Recommendations for Accommodations

I recommend that Cyn work routinely from her home office and come into the office on an “as needed” basis — for example, for in-person training sessions or All Hands meetings. She is currently managing the anxiety while coming in a handful of times each month. Although her symptoms are triggered by driving in DC-area traffic, she is currently persevering. I do not recommend any requirements for additional days working in the office; such requirements would trigger and exacerbate her anxiety, concentration, and focus issues.

Working from home routinely will provide Cyn with a stable sensory environment, reduced anxiety, and greater concentration and focus. It will ameliorate many of her symptoms of autism and anxiety.

ADA Accommodation Request for Evan — Department of Commerce

November 20, 2023

By late 2023, the playbook had matured. I'd written my own ADA request earlier that year. Now Evan was starting a new position with the Department of Commerce, and the same federal workplace that had triggered my own anxiety had a different set of triggers waiting for him.

Different symptoms, same paperwork. I wrote this letter for Evan's clinician to sign — same approach I'd been using since 2010. The diagnosis was Evan's. The accommodations were Evan's. The author was me. And the signature, when it came back, was the clinician's.

* * *

I am writing this letter regarding my client Evan Snow for the purpose of reasonable accommodations at his new place of employment. Evan has a diagnosis of Autism (F84.0) and is able to function quite well vocationally and academically. However, Evan struggles with symptoms of autism, specifically sensory overload issues, that strongly impact his ability to concentrate and thereby do his best work.

Evan will definitely perform better and be a more productive employee with the agency if he is able to telework from home on most of his days. Evan can occasionally go into the office, but the demands of getting there, and handling that environment on a regular basis, will place an undue burden on Evan while he starts this new job.

Sensory Concerns

Evan is very noise-sensitive and can hear everything around him much more strongly than anyone else. I am requesting that Evan not have to come into the office, especially on what he calls “Anchor Days” — which, from my understanding, are the days when everyone is in the office. Evan has said he finds it overwhelming and very distracting, and that it's hard to focus. In general, Evan will be a better employee if he only has to telework except for rare occasions, and those rare occasions should not be when everyone is there.

- He should be notified in advance of planned fire drills and allowed to exit the building.
- Unexpected loud noises are upsetting.
- He gets very anxious about auto-flushing toilets and will not use them. He should be allowed to use a private toilet if one is available.

Processing Speed and Sleep

Another symptom of Evan's autism that strongly impacts his functioning is his processing speed and fluency. Evan transitions very slowly — everything just takes longer for him.

Evan also has difficulty falling asleep and sometimes has insomnia, which can mean he starts work later than usual. However, he will always work the amount he is supposed to work and complete what he is supposed to do that day. Because of his sleep issues, having the flexibility to go into the office when he has had enough sleep and is able to drive safely would be ideal.

Social Anxiety

Social anxiety is another reason not to go into the office. It creates stress having to navigate the multiple social interactions that are the foundation of a work setting. Headphones would make him stand out. If he becomes overwhelmed, he may also stand out by engaging in stimming — in his case, body movements and vocalizations — which may create distraction for co-workers.

Recommendation

I believe the best match for both Evan and his new job is telework with the occasional need to go into the office on non-crowded days, or the choice to go in a few days per pay period. It would be good for Evan to occasionally go into the office, but honestly, it's better for his job and overall productivity and success that he telework a majority of the time and certainly not go into the office when it is crowded.

If I can be of further assistance, please don't hesitate to contact me.

ADA Testing Accommodation Request

April 4, 2025

This one is recent, and it's a different chapter of advocacy. Evan is an adult now, but as any autism mom will tell you, you never really stop. You just change roles.

He took the CPC Certification Exam the first time with no accommodations — four hours in one seat, no breaks, no support. It went exactly as badly as you'd expect. For the second attempt, we wrote this letter to his doctor together. Evan signed it as the patient. I signed it as the parent who still shows up. The doctor signed his portion. We submitted it through the ADA, and Evan was approved for every accommodation we requested.

* * *

Dr. Kleppa,

We are writing to respectfully request your support in obtaining testing accommodations for your patient, Evan Snow. Evan is preparing to retake the CPC Certification Exam — a 4-hour, 100-question multiple-choice examination — and we are seeking your medical evaluation and certification of his diagnosis and related functional needs to accompany an ADA Exam Accommodation Request form for submission.

Evan took this exam approximately two weeks ago without any accommodations in place. He was unable to pass. The sustained, uninterrupted concentration required over four hours proved to be a significant barrier — not a reflection of his knowledge or preparation, but of the neurological demands the testing environment placed on him. As you know, Evan is autistic, and the standard exam format does not adequately account for the challenges associated with his diagnosis.

Requested Accommodations

We are requesting that Dr. Kleppa certify that Evan's autism diagnosis supports the following accommodations:

- **Extended Testing Time:** Evan requires additional time beyond the standard 4-hour window to process questions without the compounding cognitive fatigue that affects autistic individuals under timed conditions.
- **Scheduled Breaks (Every Hour):** Evan needs a structured break at the end of each hour of testing. These breaks are essential for sensory and cognitive regulation, allowing him to reset and continue performing at a functional level.
- **Private Testing Room:** Evan self-regulates through stimming behaviors, including arm flapping. While this is a healthy and necessary coping mechanism for him, it can be disruptive in a shared testing environment. A private room would allow Evan to stim

freely without concern for other test-takers, and without the added stress of suppressing natural regulatory behavior.

- **Use of Personal Earbuds/Music:** Evan benefits significantly from listening to music on his own earbuds during focused tasks. Music serves as an auditory anchor that helps him maintain concentration and reduces sensory distractibility — a documented challenge associated with autism spectrum disorder.
- **Permitted Beverage — Energy Drink:** We would also request that Evan be permitted to have an energy drink in the testing room. Maintaining focus and alertness over an extended exam period is a particular challenge for autistic individuals, and this accommodation would support sustained cognitive engagement throughout the test.

We are asking that you provide a medical evaluation letter on your practice letterhead confirming Evan's autism diagnosis and certifying that the accommodations listed above are medically appropriate and necessary given his condition. This letter will be submitted alongside the formal ADA Exam Accommodation Request form for review and approval.

Evan has worked hard to prepare for this certification, and with the right support in place, we are confident he can demonstrate his knowledge and competency. We are deeply grateful for your time, your care for Evan, and your willingness to advocate on his behalf. Your support means everything to us.

Thank you, Dr. Kleppa.

Signed: Evan Snow and Cyn Snow

What I Wish Someone Had Told Me

If I could sit down with the version of myself who was 32 years old, with a four-year-old who was about to receive an autism diagnosis and a two-year-old who would receive his own a few weeks later, here is what I would say.

1. Nobody is coming to write the letter for you.

Doctors, teachers, principals, case managers, IEP coordinators, HR departments, testing services, college disability offices — none of these people will produce the letter you need on their own. They are not bad people. They are people with jobs that do not include writing your kid's accommodation letter from scratch. Once you accept that, you stop waiting. You write the letter. You hand it to them to sign. They sign it. The thing you needed gets done.

Write down the smallest stuff, too. Therapy bathrooms. Hand-dryer triggers. Bus stop locations. The peer who has a calming influence on yours. The teacher who is not authoritarian. The accommodation that worked best for Brian — a bean bag in an administrative space and a chill pass to go decompress — was something he used exactly once in seven years. The option mattered more than the use. The smallest stuff is what makes the biggest stuff possible.

This is true at age 4. It is true at age 14. It is true at age 25. It is true when you are the patient instead of the parent. I have been writing my own version of this letter, in one form or another, for over two decades. The template never really changes. The kid does.

2. The variable is the adult in the room.

You will spend years building the perfect IEP, the perfect accommodation list, the perfect transition plan, the perfect bus stop arrangement. None of those documents will save you if your kid is in a room run by an adult who does not see him. All of those documents will be unnecessary if your kid is in a room run by an adult who does.

Build the documents anyway. They are insurance. They are leverage. They are the floor. But understand that the actual quality of your kid's day depends on whether a Rebecca Bell or an Amy McMillan or a Becky Clarke or a Sra. H. landed in his schedule that year. You can't control that. You can only stay close enough to recognize it when it happens, thank the people who showed up, and try to take them with you when your kid moves up a grade level.

Most teachers want your kid to succeed. Most administrators do too. The system fails not because the people inside it are malicious but because it was designed for kids whose nervous systems work a certain way, and yours doesn't. Occasionally you will encounter someone who has decided your kid is the problem. That person is not a hill you can win. Document, escalate, move on. Save your energy for the people who are reachable.

3. Push back. Then recover.

You will disagree with the school. You should. You know your kid better than they do. Push back politely, with evidence, with concrete suggestions, and with the specific kid in mind.

Then — and this is the part nobody teaches you — when the school pushes back at you, recover. Apologize for the framing, not the data. Reframe institutional criticism as kid-specific experience. Take partial responsibility for the friction. Close warm. The teacher is going to be in the room with your kid until June. The relationship is the whole point. You are not trying to win an argument. You are trying to keep a kid in a classroom with an adult who is still on speaking terms with you.

4. The work compounds.

Every letter you write makes the next letter easier. Every relationship you build with a teacher becomes a template for the next relationship. Every accommodation you negotiate gets reused, refined, and renamed for the next school. By the time your kid is in high school, you will have a binder of templates and a head full of phrases and a Rolodex of people who have shown up for your kid. By the time your kid is an adult, you will still have all of that, and you will use it to help him write his own letters.

None of this is wasted. None of it. Even the years that felt like nothing got better — the restraints, the suspensions, the manifestation meetings, the moves between school districts — were depositing something. The kid you are advocating for is becoming the adult who knows what self-advocacy looks like because he watched you do it for years.

5. Eventually you will write the letter for yourself.

This is the one nobody tells you. You spend twenty years learning how to translate your kid's nervous system into administrative language. One day, you sit down to write an accommodation letter for yourself, and you realize you already know exactly how to do it, because you have been practicing on your kids for two decades.

Some of you reading this are autistic and don't know it yet. Some of you reading this are autistic and do. Some of you have been told you have anxiety, or depression, or ADHD, and those things are also real but they are not the whole picture. The diagnostic landscape for autistic women, in particular, is still catching up. Many of us are diagnosed in our forties or fifties, after a child, often after multiple children. This is not a coincidence.

If that turns out to be your story too — and statistically, if you are reading this as the mother of an autistic kid, there is a reasonable chance it will — you will already know how to advocate for

yourself. You have been doing it for everyone else for years. You just have to put your own name at the top of the next letter.

6. The kid you are advocating for is worth it.

I know you know that. I am saying it anyway. Some days you will not believe it. Some days the cost of advocacy will feel higher than the worth of advocacy. Some days you will be sitting in your car after an IEP meeting wondering if it would have been simpler to never have had this kid. Most days you will know better. Some days you will not.

On the days you don't believe it, here is what I want you to remember. The kid you are advocating for is going to grow into an adult who has a life because you fought for him. He will have favorite places. He will have friends. He will have a job, or a craft, or a passion, or all three. He will love things you cannot predict, and he will tell you about them in his own way, and you will know, on those days, that every letter you wrote was for this. That every chocolate box you sent was for this. That every recess plan and every bus stop adjustment and every chaperone sign-up and every email at 5 a.m. was for this.

My kids are 29 and 27 as I write this. Brian lives independently near Annapolis. Evan is starting a federal career. Both of them know exactly who they are and what they need. Neither of them got there by accident.

Your kid will get there too. Keep writing the letters.

* * *

This is the end of the document. If any of this was useful, take it. Adapt it. Pass it on. The work is not proprietary. It is what we owe each other.

— Cyn

- Over his academic career, Evan’s accommodations included:

⎫ Being pulled outside prior to fire drills & accommodations for bus drills

⎫ Designated bathroom (no hand dryers, no auto flushes, no locker rooms)

⎫ A change of schools within-district, from our neighborhood elementary school to another

nearby school that had a stronger special education program. This accommodation was

granted based on a letter that I wrote to the school board (signed by his doctor) advocating for the change which included strong supporting rationale. We were told no at first, and I had to appeal, but eventually got the boys in the stronger special ed program school.

⎫ Parapro or school aide when appropriate

o Help focus on developing reading strategies: inferencing, predicting, sequencing

⎫ Small group activities when appropriate

⎫ Subtitles for the hearing impaired on instructional videos since he absorbs what he reads better than he picks up verbal information

⎫ A ball chair instead of a regular desk chair

⎫ School bus pick-up and drop-off right in front of our house (the regular bus, not the special ed bus).

⎫ One-on-one special ed and/ or small group pull-out for subjects in which he struggled

⎫ We worked with his teachers early on to teach him using materials or examples related to his areas of interest, and that this would make their job easier and greatly benefit him. Whenever possible, they encouraged him to do research or projects on a topic which held his interest, such as football or travel. He didn't like to read, so he was encouraged to pursue SpongeBob books, which he found interesting. This was a very effective, floor time type of approach using a carrot to entice him to engage academically.

⎫ Reduced/ modified homework

⎫ Receive schedule changes in advance whenever possible

⎫ Organizational support for class materials including extra storage

⎫ Graphic organizers for written tasks

⎫ Reduced distractions for testing

⎫ School-provided OT/ PT/ SLT

o Pragmatic language and nonverbal communication skills were areas of particular focus

⎫ Consistent special educator /case manager throughout all four years of high school

⎫ Testing accommodations (Extra time & human reader for tests)

⎫ Typing notes on a laptop or netbook. His OT timed his written ability vs. his typing speed and it wasn't even close. His handwriting is laborious and barely legible.

⎫ Early access pass to each new school year. We'd visit the school the week before classes began to take a private tour, learn locations of classrooms and lockers, and meet teachers. We avoided crowded back-to-school nights.

⎫ Written class notes provided; teacher's notes best

⎫ Field trip support. Note: I chaperoned almost all of his field trips to ensure his toileting and dietary needs were accommodated.

⎫ Duplicate set of school books for use at home

Outside of school, we traveled whenever we could…it was a critical piece of the puzzle to break down walls and get through to Evan. He came alive, tuned in and fired on all cylinders when on the road. Airplanes, boats, taxis, and trains were locomotion therapy and worked miracles on Evan. It was one of the few opportunities we had where he was maximally engaged.

From an advocacy perspective, I would get in touch with the school and arrange for travel time to be counted as excused absences. Typically, there were no issues, as long as Evan completed a project about his travels. Over the years, he created video diaries, wrote essays and short stories

- about his adventures. One of his speech therapists even wrote in her recommendations "take advantage of unusual or unique situations to practice social skills…Typically, a student will retain information learned in a novel situation better than information learned during a regular routine…the uniqueness of the situation will help with later recall."

When she made these recommendations, she didn't have travel experiences in mind, but I'm like, wow…this directly supports what we've discovered works for Evan, so great!

Without a doubt, these experiences were as much or more meaningful for his growth than time spent sitting in a classroom. I cherish each and every memory from these trips.

Let's take a look at some of Evan's academic career.

Evan was on the Georgia Autism Deeming Waiver, and we were beyond blessed that it paid for most of his private therapy. After a summer of intensive therapy, I wanted him to continue an abbreviated therapy schedule while enjoying a part-time day in kindergarten.

- The following is a letter that I wrote in pursuit of this goal, and obtained his pediatrician's endorsement and signature in August 2004:

Dear Ms. Littlefield,

I am writing regarding Evan Nieves, scheduled to be in Ms. Welch's kindergarten class this year.

Evan will require early dismissal from school daily as a result of the necessity of his attendance in

Occupational Therapy, Physical Therapy, Speech Language Therapy, Floortime Therapy, and private

Applied Behavior Analysis therapy. These therapies are essential to Evan's continued improvement in his

sensory, motor, cognitive, and social deficits. His schedule may vary, but tentatively is as follows:

Monday: Speech therapy at 2 p.m. with a 1:30 p.m. dismissal (subsequent therapies follow).

Tuesday: Floortime therapy at 1:30 with a 1:00 dismissal (subsequent therapies follow).

Wednesday: Floortime therapy at 12 p.m. with a 11:30 dismissal (subsequent therapies follow).

Thursday: Verbal behavior/ABA therapy at 2 p.m. with a 1:30 dismissal (subsequent therapies follow).

Friday: Aquatics Physical Therapy at 12 p.m. with an 11:30 dismissal (subsequent therapies follow).

Mrs. Nieves is currently in touch with Ms. Welch, and they are discussing ideas to minimize disruption to the classroom. They are working together to make Evan's daily dismissal process seamless.

Thank you for your attention to this matter. Please contact this office if you have any questions.

Sincerely,

Dr. Boudreaux MD

- 2004 - 2005 May Evan finishes Kindergarten?

After a fabulous Kindergarten year with two of the finest special ed teachers ever, Ed and I attended Evan's IEP meeting to get him set for first grade. But we realized that between Evan's shared aide and these two fabulous teachers, we had a great thing going. With that in mind, we coordinated with our therapists and put together a request for Evan to remain for another year in Kindergarten with Ms. Welch and Ms. Cregge. At this point in his development, I'm not concerned about him learning math and ABCs as much as being nurtured and encouraged to create and explore. Even though it set him back a year relative to his peers, it was a smart investment.

- 2008 Swansfield – Evan's notes for IEP:
    - Request subtitles on all films or media
    - Needs socialization
    - Flapping on playground – needs sensory breaks/ sensory room
    - Behavior goals include
        - 30 minutes per week with Jasmine
        - One recess per week facilitated (facilitated playground time)
    - Working on one and two-step commands
    - Use music as an effective means to "reset" Evan, as well as sensory breaks
    - Use educational software
        - To reward

- To educate

• Ensure he has a FULL recess – not a ½ recess (some students misbehavior would shorten recess which would upset Evan to the point of losing it).

- He moves more slowly than others (he's more deliberate and slow)

For multiple years: Always arrange a quiet meet-and-greet before school starts

• E.g., on day that teachers are setting up their classrooms but before the formal meet-and-

greet night.

• Coordinate with the special needs POC to guide

2012 May

Evan's sixth grade class went on a week-long environmental field trip to North Bay, XY. Evan's not fond of environments over which he has no control, especially as a middle schooler where adults tend to think they know best, and impose their will. Evan stayed behind where his environment is predictable, and I support him. He's not the only student who did not attend, and the remaining students, although still attending classes, have a light week. Mr. George scheduled a chess tournament wherein each round, the winner would continue to the next round. Guess who was crowned chess king? Evan!! He's so proud of himself, as am I. All those hours on the computer playing Fritz and Chesster paid off!

- 2014 to 2018

Evan's high school years were relatively uneventful, at least in comparison to some of the struggles of his earlier school years. There was an occasional bomb threat or the time a kid tried to burn something in the boys' bathroom and created a massive fire evacuation…both events with alarms, sirens and unanticipated chaos.

As soon as he got his driver's license, he began spending more time at school than at home. He went to every single sporting event, for men's and women's teams, from field hockey and

- Over his academic career, Evan's accommodations included:

  - Being pulled outside prior to fire drills & accommodations for bus drills

⎪ Designated bathroom (no hand dryers, no auto flushes, no locker rooms)

⎪ A change of schools within-district, from our neighborhood elementary school to another

nearby school that had a stronger special education program. This accommodation was

granted based on a letter that I wrote to the school board (signed by his doctor)

advocating for the change which included strong supporting rationale. We were told no

at first, and I had to appeal, but eventually got the boys in the stronger special ed program

school.

⎪ Parapro or school aide when appropriate

o Help focus on developing reading strategies: inferencing, predicting, sequencing

⎪ Small group activities when appropriate

⎪ Subtitles for the hearing impaired on instructional videos since he absorbs what he reads

better than he picks up verbal information

⎪ A ball chair instead of a regular desk chair

⎪ School bus pick-up and drop-off right in front of our house (the regular bus, not the special ed bus).

⎪ One-on-one special ed and/ or small group pull-out for subjects in which he struggled

⎪ We worked with his teachers early on to teach him using materials or examples related to

his areas of interest, and that this would make their job easier and greatly benefit him. Whenever possible, they encouraged him to do research or projects on a topic which held

his interest, such as football or travel. He didn't like to read, so he was encouraged to pursue SpongeBob books, which he found interesting. This was a very effective, floor time type of approach using a carrot to entice him to engage academically.

⎫ Reduced/ modified homework

⎫ Receive schedule changes in advance whenever possible

⎫ Organizational support for class materials including extra storage

⎫ Graphic organizers for written tasks

⎫ Reduced distractions for testing

⎫ School-provided OT/ PT/ SLT

- o Pragmatic language and nonverbal communication skills were areas of particular focus

⎫ Consistent special educator /case manager throughout all four years of high school

⎫ Testing accommodations (Extra time & human reader for tests)

⎫ Typing notes on a laptop or netbook. His OT timed his written ability vs. his typing speed and it wasn't even close. His handwriting is laborious and barely legible.

⎫ Early access pass to each new school year. We'd visit the school the week before classes began to take a private tour, learn locations of classrooms and lockers, and meet teachers. We avoided crowded back-to-school nights.

⎫ Written class notes provided; teacher's notes best

⎫ Field trip support. Note: I chaperoned almost all of his field trips to ensure his toileting and dietary needs were accommodated.

⎫ Duplicate set of school books for use at home

Outside of school, we traveled whenever we could…it was a critical piece of the puzzle to break down walls and get through to Evan. He came alive, tuned in and fired on all cylinders when on the road. Airplanes, boats, taxis, and trains were locomotion therapy and worked miracles on Evan. It was one of the few opportunities we had where he was maximally engaged.

From an advocacy perspective, I would get in touch with the school and arrange for travel time to be counted as excused absences. Typically, there were no issues, as long as Evan completed a project about his travels. Over the years, he created video diaries, wrote essays and short stories about his adventures. One of his speech therapists even wrote in her recommendations "take advantage of unusual or unique situations to practice social skills…Typically, a student will retain information learned in a novel situation better than information learned during a regular routine…the uniqueness of the situation will help with later recall." When she made these recommendations, she didn't have travel experiences in mind, but I'm like, wow…this directly supports what we've discovered works for Evan, so great!

Without a doubt, these experiences were as much or more meaningful for his growth than time spent sitting in a classroom. I cherish each and every memory from these trips.

- Let's take a look at some of Evan's academic career.

Evan was on the Georgia Autism Deeming Waiver, and we were beyond blessed that it paid for most of his private therapy. After a summer of intensive therapy, I wanted him to continue an abbreviated therapy schedule while enjoying a part-time day in kindergarten.

The following is a letter that I wrote in pursuit of this goal, and obtained his pediatrician's endorsement and signature in August 2004:

Dear Ms. Littlefield,

I am writing regarding Evan Nieves, scheduled to be in Ms. Welch's kindergarten class this year.

Evan will require early dismissal from school daily as a result of the necessity of his attendance in.

Occupational Therapy, Physical Therapy, Speech Language Therapy, Floortime Therapy, and private.

Applied Behavior Analysis therapy. These therapies are essential to Evan's continued improvement in his sensory, motor, cognitive, and social deficits. His schedule may vary, but tentatively is as follows:

Monday: Speech therapy at 2 p.m. with a 1:30 p.m. dismissal (subsequent therapies follow).

Tuesday: Floortime therapy at 1:30 with a 1:00 dismissal (subsequent therapies follow).

Wednesday: Floortime therapy at 12 p.m. with a 11:30 dismissal (subsequent therapies follow).

Thursday: Verbal behavior/ABA therapy at 2 p.m. with a 1:30 dismissal (subsequent therapies follow).

Friday: Aquatics Physical Therapy at 12 p.m. with an 11:30 dismissal (subsequent therapies follow).

Mrs. Nieves is currently in touch with Ms. Welch, and they are discussing ideas to minimize disruption to the classroom. They are working together to make Evan's daily dismissal process seamless.

Thank you for your attention to this matter. Please contact this office if you have any questions.

Sincerely,

Dr. Boudreaux MD

- 2004 - 2005 May Evan finishes Kindergarten?

After a fabulous Kindergarten year with two of the finest special ed teachers ever, Ed and I attended Evan's IEP meeting to get him set for first grade. But we realized that between Evan's shared aide and these two fabulous teachers, we had a great thing going. With that in mind, we coordinated with our therapists and put together a request for Evan to remain for another year in.

Kindergarten with Ms. Welch and Ms. Cregge. At this point in his development, I'm not concerned about him learning math and ABCs as much as being nurtured and encouraged to.