

# Addendum:

## *Decoding Autism and Leading the Way to Successful Inclusion in the Context of the Coronavirus Pandemic*

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Last spring, my edited manuscript headed off to the printer. By the time it returned as an actual book—*Decoding Autism and Leading the Way to Successful Inclusion* (Boroson, 2020) —the world had turned upside down. And now we educators find ourselves on the front lines of a war none of us expected to fight, battling an enemy that is more insidious (and, dare I say, *covidious*) than any we’ve fought before.

Education leaders are scrambling to find new ways to maintain high standards for education without jeopardizing their students’ physical health and emotional well-being. We are diving deep into new methods of pedagogic delivery, including socially distanced in-person instruction, revolving cohorts, and fully remote instruction, as well as various permutations and combinations thereof.

Even as we seek to master each of these new and different methodologies, we must also remain nimble and ready to shift gears at a moment’s notice. Educators are going to need to *use themselves in flexible ways, armed with plenty of ingenuity, agility, aptitude, determination, and resilience to meet each moment, however it presents itself*. As it happens, those are the very same skills students on the autism spectrum have always needed from educators. Those are the skills required to provide a robust, differentiated education.

And just as they did in pre-covid-19 times, your students on the spectrum need you to stretch yourselves into differentiated directions. My book is here to provide

lots of practical information and useful strategies to help you and your teachers differentiate education for students on the autism spectrum within inclusive schools and inclusion classrooms. Now let's look at ways to differentiate your inclusive program to meet the moment of the coronavirus pandemic

## **Anxious Much?**

How are you feeling about life during this pandemic? Are you fearful for your own well-being? Unclear about what's coming next? Unsure what you need to do and how best to do it? Worried about pleasing all of the people who are invested in your decisions? Eager to do your best to get it right but uncertain about what "right" actually is? Well, this is pretty much what life on the autism spectrum feels like. Our students on the spectrum grapple with these same fears almost all of the time—even with no pandemic.

Chapter 3 of my book takes a close look at the anxiety that is prevalent among students on the spectrum. These students tend to think in rigid, concrete ways. For this and other reasons, they generally feel safest when their lives and school days are clearly structured and highly predictable. That's why teachers of students on the autism spectrum find that the use of clear and specific schedules is indispensable in the classroom. But even then, anxiety is always buzzing, just below the surface.

Now take that intense, baseline apprehension, whip it up with an invisible, deadly, and uncontainable pandemic, and it's a recipe for incapacitating anxiety.

Going to school has been a fundamental and reliable component of our students' daily routine for as long as most of them can remember; they depend on its consistency to maintain their equilibrium. School is often a comfort for students on the spectrum because it's associated with a whole set of not only external rules, but also internal rules that these students cling to. Here are some examples:

- ✓ The school day always begins with the principal announcing over the public address system, "Goooooooooooo morning, Aardvarks!"
- ✓ Learning happens in Room 173 in the school building, or in an orderly sequence of specific rooms in the school building.
- ✓ Lessons are consistently delivered by a teacher in a classroom.
- ✓ The school day proceeds according to a specific schedule.

Here's another:

√ Masks are for Halloween. Period.

In the time of covid-19, rules like these are being violated, and the “new normal” doesn't look like anything our students expect or need it to be. For example, now:

- λ The school day starts and ends—and starts again—at all different times with no announcements and no aardvarks.
- λ Learning happens through the computer—and *in the living room!*
- λ Mom, Dad, or Grandma acts like a teacher.
- λ The schedule is changing all the time.
- λ And *masks?* Ugh! (More on masks below.)

It's all wrong. And that's not OK with students on the spectrum. When every day presents this much cognitive dissonance, anxiety is triggered 24/7.

Other formerly reliable aspects of life have changed, too. There are lots of new rules to learn about being outside and around others, and there's a new intensity among adults as they enforce those disorienting new rules.

Depending on the ever-changing status of the pandemic, extracurricular activities that used to help anchor the week—such as social skills groups, applied behavior analysis (ABA) therapy, and swimming lessons—may have vanished from their schedules. Periodic incentives—such as a trip to a favorite gaming or Lego store, or a visit to the library or the ice cream shop—may be inconsistently or entirely unavailable.

Even when students are back to school, it's simply not what it used to be. Most of the anchors that made school the reliably safe haven that it was have floated away. Instead of what they remember and may have longed for, they find new seating rules on the bus and in the classroom, staggered start and dismissal times, one-way hallways, reduced class sizes, revolving schedules, enforced social distancing, plexiglass partitions, and mandated mask-wearing and hand-washing. Almost nothing is the same.

Of course, the most painful and difficult result of the coronavirus pandemic is loss of life. Some students may have lost parents, grandparents, aunts, uncles, siblings, babysitters, or others who were very important to them. Your school may even have lost staff and students to the virus. If that's the case, you'll have your hands full setting up emotional supports for all of your grieving students and staff. Just keep in

mind that beyond struggling with the expected grief that results from losing loved ones, students on the spectrum may struggle to adapt to potentially new caregiving styles, arrangements, rules, and schedules.

To help manage their anxiety, students on the spectrum often cling to concrete information because it seems dependable. They might perseverate on *dates*, as in “What day is this virus going to be over?” or “Just tell me when school is going to open again for good.” Others, who understand more, may perseverate on *data*, as in “What percent of positive cases can we have in this school before it shuts down again?” Since dates and data are scientifically determined and objectively reliable, students on the spectrum depend on them to help make the unknown feel more predictable.

You may find that your students’ heightened anxiety manifests in the form of extreme perseveration, incessant and repetitive questioning, irritability, or inability to focus. Encourage teachers to provide as much concrete structure and overt organization as possible, just as they would in a standard classroom situation, especially regarding the new rules and changed systems. The strategies provided in Chapter 3 will help you and your teachers find ways to create schedules, routines, and rules that will ease the extreme anxiety your students on the spectrum face, even during this challenging time.

## **New Sensations**

In addition to the perceived wrongness of the *idea* of wearing a mask all day every day, the *fact* of wearing a mask is fraught with distress for many students on the spectrum. As described in Chapter 4, most students on the spectrum have highly responsive sensory systems that can cause overwhelming sensory discomfort. Masks present a host of comfort challenges that are sensory in origin such as the feeling of paper or fabric on their face, the heat and condensation caused by breathing into an enclosed space, the pressure of the wire on the nose, and especially the pull of the strap around the ears or head. Those irritating feelings that vex us all, can be painful or genuinely unbearable for them. Discomfort can trigger loss of focus or refusal to comply and other difficult behaviors.

When students struggle to wear masks, encourage teachers to hold mask-making activities as a way of granting students some ownership and control over their own mask and an opportunity to individualize their mask in ways that engage them in

the *idea* of actually wearing it. Masks can feature beloved characters, favorite quotes or sayings, emojis, hand-drawn pictures or designs, homemade tie-dye designs, and many other forms of self-expression. See Chapter 6 to learn more about ways to engage reticent students in necessary learning.

That buy-in alone may ease some sensory distress. But it may be necessary to make additional, practical adjustments to ensure that students are able to tolerate the feeling of a mask on their face. Be ready to try differently textured, layered fabrics (e.g., paper, cotton jersey, flannel, satin); various ways to secure them (e.g. around the ears or around the head; using elastic, string, or ribbon; or even attached to a baseball cap), and assorted shapes (e.g., wide fabric headbands or gaiters or balaclavas made of polyester or spandex).

As is always the case with students on the autism spectrum, their responses to various kinds of input can run the gamut from one extreme to another. So, while some students will struggle to adapt to the wrongness of wearing face masks on non-Halloween days, others will embrace the consistency of the new mask-wearing rule, especially as so many old rules have fallen away. These students may comply eagerly with the face mask rule; so much so, in fact, that they may become rule enforcers, approaching peers, adults, and even strangers on the street to insist that they wear a mask and wear it properly.

Additionally, visual-spatial challenges may make it impossible for students on the autism spectrum to retain an accurate visualization of what six feet of social distance looks like. Even under the best of circumstances, these students may be space invaders. During socially distant times, they may need especially clear and concrete indicators of where to sit, where to stand, which side of the hallway to walk on, and how much distance to maintain from others.

Use the ideas presented in Chapter 4 to help you recognize whether sensory challenges are at the root of difficult behaviors and to develop strategies to ease the sensory stress on your students. And turn to the strategies in Chapter 6 to help teachers “find the hook” that will help their students lean into these new cognitive challenges.

## **Home Sweet School**

Although students on the spectrum tend to enjoy using computers, even more than most children they prefer to make their own choices about how they utilize their

screen time. And for students on the spectrum, independent online learning may be a non-starter. Many will have difficulty with the demands of remote auditory processing, transcribing from the screen, and maintaining attention and visual focus—to name just a few challenges. Moreover, many will be distracted by the fundamental incongruity of trying to learn academic content on a screen that usually hosts Moana, Mario, or Minecraft or of spending the so-called “school” day in a room that also contains a puppy and a cabinet full of cheese doodles. School no longer feels like school, and home doesn’t exactly feel like home anymore, either.

Even as you and your staff are pulled in extreme new directions, please be aware that these students are going to need more guidance, more instruction, more structure, more support, more 1:1 contact, and more encouragement than your other students, just as they do in conventional circumstances.

Encourage teachers to create templates that make it easier to provide the kinds of differentiated support individual students need. For example, teachers might write out a detailed set of instructions for logging on to Zoom or Google Classroom, annotated with photos of the process; if all students have a copy of these at home, it can help prevent situations in which, for example, the whole class repeatedly has to wait for one or two students to remember how to turn their device’s video on and audio off. Digital templates and graphic organizers can also be enormously helpful to structure assignments during these disorderly and disorganized times. Chunking activities into small tasks that are achievable even when focus is fleeting will also be especially important to support sustained learning.

Take a look at Chapter 6 for strategies that facilitate students’ ability to engage in any kind of content and to assimilate it in ways that are meaningful and durable.

## **Mandated Services**

With all you have to focus on these days, ensuring that your students who have special needs are receiving their mandated related services may not be high on your list. But it needs to be. Related services are key to the progress of students on the autism spectrum; the hard-won gains they have achieved over time are easily lost. The reason many students who have special needs are granted 11- or 12-month school years is that skill regression is very real. If you don’t have space to attend to this issue yourself, please designate someone you trust to ensure that every single student’s

mandates are being met, one way or another. Not only is it crucial; it's the law. Take a look at Chapter 1 for a refresher about mandated services and other programmatic options.

## **Not Your Problem, But Still...**

Bear in mind that the anxiety, sensory, and other challenges that have come to the fore at home during this period have been acute, protracted, and profound. With their equilibrium utterly upended, most students on the spectrum have been intensely affected by these affronts to their status quo. Their responses usually present loudly, dramatically, insistently, and relentlessly, requiring frequent or even constant attention and intervention by parents, guardians, and caregivers. Find out why responses are so big and loud and collect strategies to help allay them in Chapter 3.

Moreover, since independent learning is more difficult for these students than for others, parents and guardians must take an even more active role in supporting their children's education. Distance learning in a pandemic is an inherently stressful and highly charged environment for everyone; for families with children on the spectrum, it can be a firestorm. Take a look at Chapter 8 to understand exactly how challenging it can be to live with a student on the spectrum, *even in the best of times*.

Extreme behaviors and special learning needs add enormous stress to families who are already struggling to sustain the daily strain of autism. Now they may be overwhelmed by the demands of supporting the distanced education of one or several children as they also try to manage their own employment, social isolation, acute health risk, and financial insecurity.

Be gentle with your students. Be gentle with their parents and guardians. Be gentle with your teachers and be gentle with yourself. We're all going through an awful lot.

## **Staying Apart Together**

As you reimagine and reinvent creative new configurations of students—such as revolving in-person schedules, “learning pods,” or “quaranteams,” with an eye toward ease of contact tracing, please consider this: It has taken disability advocates more than 50 years to change paradigms so that today, a plurality of students on the

spectrum spend at least 80 percent of their day in general education/inclusion classrooms (U.S. Department of Education, 2019). And that's still a work in progress. In all likelihood, your teachers will find it easiest to create student pods or teams that are academically homogeneous. While easing the way is a crucial priority for these times, I ask you to work to uphold the progress that has been made in terms of inclusion. Please try to maintain diversity and inclusivity in your classrooms, in whatever form your classrooms take. This pandemic has compromised our health and safety; it has robbed us of many of the freedoms we took for granted; it has taken the lives of beloved friends and family members worldwide. Please don't let it take the hard-won dignity that students on the spectrum gain through living and learning among their typically developing peers. In this unprecedented time, our focus as educators and caregivers must be on mutual support and undiscriminating kindness and patience, as we hunker down together, six feet apart.

*Sources:*

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