BUILDING

BRIDGES Across the Autism Spectrum

To best serve students with special needs, honor the collective wisdom of both parents and educators.

Barbara Boroson

Let's face it: Students on the autism spectrum bring a vast array of challenges into the learning environment: relentless anxiety, repetitive preoccupations, limited social skills, extreme sensory responses, executive dysfunction, idiosyncratic speech and/or language, gross and/or fine motor delays, disruptive behaviors, and more. That's a lot for any student to handle—and no easy feat for us as educators either.

However, even in the context of these profound difficulties, there is one particular challenge that teachers and administrators of students on the spectrum report as the most vexing.

It's not supporting communication or sensation or socialization. It's not differentiating academics. It's not even managing behavior.

It's me.

It's parents.

It's this: *What do we do when parents just won't hear what we tell them?*

Having worked in the field of autism education for more than 25 years (as a clinician, administrator, and consultant) and having been a parent of a child with autism for 18 years, I have sat on both sides of the table for these difficult conversations, and I know, firsthand, that the feeling of frustration is mutual. Let's take a candid look at common stumbling blocks between educators and parents and explore some fundamental adjustments that can shift this dynamic from confounding to constructive. (For the sake of simplicity, I use the word "parent" to include any type of caregiver or guardian who is acting in the capacity of a parent.)

The Three Cs

To start, consider three potential areas of collaboration—consistency, continuity, and communication—that are especially crucial when working with students on the autism spectrum.

Consistency

Students on the spectrum crave consistency. When expectations are presented in ways they can understand, with consistent messaging and follow-through, these students can begin to trust the routine, set aside their fear of the unknown, and relax into the flow of the day.

Continuity

Students on the autism spectrum struggle to generalize what they learn. Executive dysfunction and other challenges make it difficult for them to expand accurately from the concrete to the abstract, so they tend to learn in extremely circumscribed ways.

For example, a 3rd grade teacher received a note from the school's occupational therapist, commending one of her students, Ian, for having achieved an ambitious handwriting goal. The classroom teacher was baffled—she had seen no improvement in Ian's handwriting. Together, the therapist and the teacher came to realize that Ian had been returning to his classroom after each O.T. session and reverting to his "old" handwriting! In response, the occupational therapist and teacher both instructed Ian to use his "new" handwriting "all the time." Once a continuity of expectations had been established, Ian was happy to comply. Until then, it hadn't occurred to him to generalize his new skill.

Continuity across contexts, whether from class to class, from school to home, or from home to school, not only boosts generalization, but also makes the day seamlessly predictable so that students can move through major transitions with confidence.

Communication

Despite their best intentions, students on the spectrum can be particularly unreliable conduits of information between home and school due to difficulties with receptive and expressive language, auditory processing, and organization. Teachers need to keep in close touch with parents to ensure that accurate information is being shared.

In 8th grade, my son came home from school one day quite agitated, insisting that everyone in our family needed to pack a bag immediately. He said his social studies teacher had told the class that a bus would pick us up at our house in an hour because we were being relocated. Despite my best logical efforts to debunk this notion, he grew increasingly anxious.

As he began packing frantically, I called the school. His teacher told me that they had been discussing the mandatory evacuations of World War II. Over the phone, I could practically hear her shaking her head. "Oh my gosh, Barbara," she said. "I can't even tell you how many times I reiterated that this was a 'what if' scenario: *What if* your family were told they had an hour? How would you feel? What would you pack?"

Contextual Differences

Parents and educators often experience the same student in such different ways that it can seem we're not talking about the same kid at all. Doubt and distrust, often triggered by underlying feelings of inadequacy on both sides, can flare up unexpectedly. Defensiveness quickly contaminates a parent-educator relationship and can slam shut any hope of meaningful collaboration going forward. The first step in breaking through this negative spiral is to openly acknowledge that one child can present quite differently in different contexts.

All's Well at School

Some students on the autism spectrum function well in school, even in general education classrooms. As educators, we may wonder why such a student has been given the diagnosis she has—at school she is attentive, cooperative, flexible, and engaged. It's easy to be lulled into believing that we know the whole child and to assume that she functions at the same relatively high level across contexts.

> We need to remind parents that growth happens in the sweet spot where a student is stretched, but not stressed.

But that same student may be exhausting and utterly overwhelming at home, and so her parents may resist your characterizations. They may feel skeptical: *There's no way my child patiently waits her turn for the computer at school. At home, she shoves her sister out of the chair.* They may feel cynical: *This teacher must have low expectations for my child because she's been labeled autistic.* They may feel inadequate: *If this teacher can get my child to cooperate, why can't I? Am I a bad parent? Is this all my fault?*

Be careful here. Though we may not verbalize judgmental feelings, unspoken negativity comes across loud and clear. Check yourself: Are you, deep down, feeling superior, even disdainful? If so, it's probably seeping through your carefully cultivated professional veneer.

Instead, set judgments aside and consider some practical reasons that students on the autism spectrum might do better at school than at home.

What's Working at School

At school, life follows a reliable, comprehensible schedule. For instance, first period is always science and Friday is always pizza day. Better yet, the school schedule may be presented in a visual, digital, or other multisensory format that promotes engagement and bolsters independence. That kind of transparent structure is very grounding for these students and may make a crucial functional difference.

What's Not Working at Home

Home may be more laid-back, as is common in many families. Chances

are, the dinner menu at home isn't posted a month in advance. As comfortable as an easygoing home may be for most of us, it may not be the best thing for everyone.

Parents often find that their child puts her best foot forward out in the world, and then falls apart at home. It can get pretty stormy when these kids come whirling off the bus like little tornadoes. Empathize with these parents who are wrung out, but also reassure them that their child has her priorities in order. She is bringing her best self to school. That's what we're all supposed to do! Home is—and should be—a safe and forgiving place to let loose at the end of a hard day's work.

Still, if parents can follow through on what's working at school, their child's best self can be generalized across contexts. In a sense, students on the spectrum can actually be *more* relaxed when their environment is a bit less relaxed. Don't hoard your heroics! Share with parents what's working: Suggest that they try the visual schedule, prompts, and strategies that the student responds to at school so parents can reap the benefits at home.

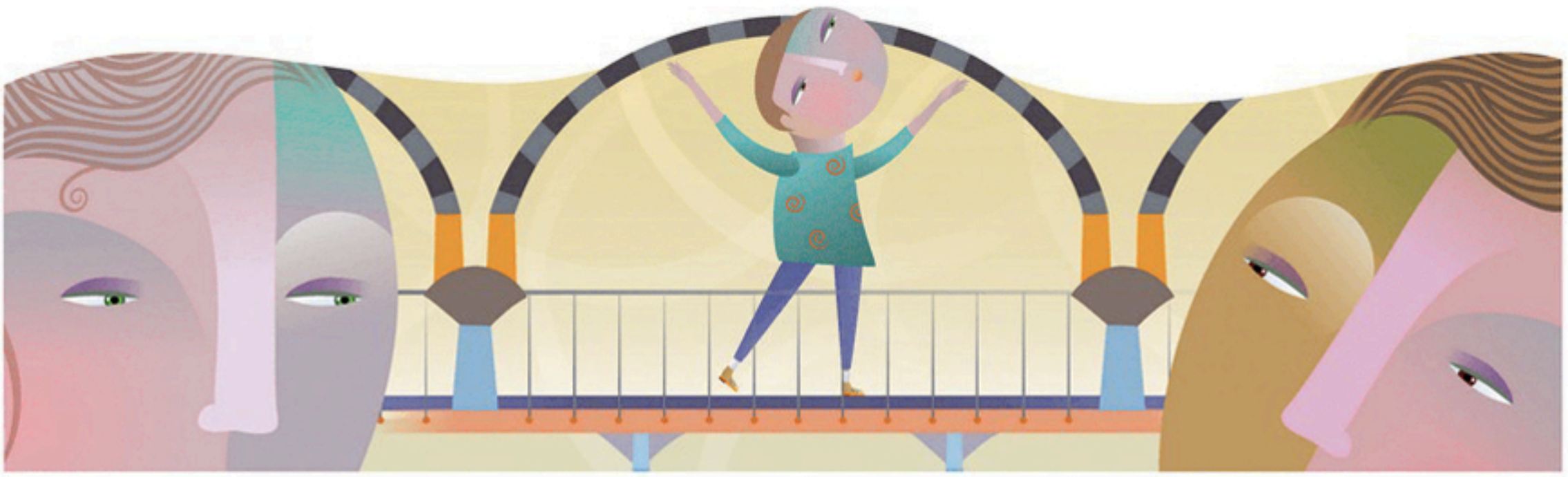
All's Well at Home

Even more common is the opposite scenario: A student is struggling significantly at school, but his parents maintain that everything is just fine at home, thank you very much.

At school, we may see a child who is constantly disturbing others and cannot work independently even for a minute.

What? Not my kid! My kid can read a whole book independently at home!

As educators, when we hear comments like that, we may doubt the parents. Truth be told, educators often disparage such comments as "denial." Remember, these are not easy conversations to have. No parents want to hear that their child is struggling or different.



But the fact is, it's not uncommon for a child to be more focused and engaged at home than at school.

What's Not Working at School

School throws relentless demands at these students. They are expected to engage, socialize, communicate, and manage the upheavals of transitions all day long. It's constant stimulation. Even when the school day is optimally scheduled and structured, for some students on the autism spectrum, it can be just too much.

What's Working at Home

Home, however, may be deeply individualized, which can make all the difference. At home, parents can do—and need to do—whatever works. My friend Carmen puts her daughter's book on the floor and lets her read in a handstand position. That's the only way her daughter can do her reading homework. That degree of flexibility may be the reason a child can, in fact, sit (or stand upside down) and read a book independently at home.

At home, a child on the spectrum may be afforded more leniency than their typical siblings are. For example, Tyler's parents and siblings have learned that it's just easier to sacrifice their own turns to go first than to try to make Tyler wait. They know that if Tyler doesn't go first, all hell will break loose, and it will take hours for the family to recover after the resultant meltdown.

For these reasons, parents may ask or expect the school to accommodate a student in ways he is accustomed to at home. It can be frustrating and worrying for parents when their hard-won wisdom is not welcome at school. And it can be equally challenging for educators to respond to parents' seemingly unrealistic requests.

Coming Together

What's missing from these fraught home-school relationships is empathy and transparency. When I consult at schools, I help educators cut through their defensiveness, validating that, indeed, some of these "home" strategies cannot be implemented at school. But I also urge educators to explain *why* that is the case. Join with

parents by acknowledging that letting Tyler go first in every game is surely a profound relief, even a necessity at home, but at school, the needs and rights of 23 other students must be upheld.

Share with parents that there's a key learning opportunity here. School is more reflective of the real world, in which, some day, all students are going to have to function to the best of their ability. Assure parents that at school, we will do our very best to differentiate, accommodate, modify, and support, but certain skills and expectations must be insisted upon for the sake of all students. Acknowledge that yes, this can make school more challenging for students on the spectrum, but if their child is carefully supported, there will be long-term benefits. We need to remind parents that growth happens in the sweet spot where a student is stretched, but not stressed. And we need to remind ourselves that the least restrictive environment doesn't mean the least supportive environment.

The Parents' Perspective

Meanwhile, it's crucial that we tune into the parents' experience. What must it be like to live with this particular child, 24–7? How might a rule like letting one child always go first have developed over time? As a parent, I can tell you there's a name for rules like this, and it's not *enabling*. It's called *survival*.

As educators, we must remain keenly aware that these parents are struggling, and that conversations about their children are emotionally loaded. Families of students on the spectrum have traveled a long road of high hopes and dashed dreams, littered with innumerable obstacles and potholes along the way. Try not to disdain or dismiss questions, concerns, and qualms as the hovering worries of "helicopter parents." Do these parents worry? You bet they do. But they have much to worry about.

Although parents of students on the spectrum usually get *less* meaningful information about school than most parents do, they have much *more* to worry about. Their kids get confused and disoriented. Their kids lose their stuff, lose their way, and lose control. They misunderstand and miscommunicate. They get bullied, teased, overstimulated, and overwhelmed on a regular basis. This makes life at school enormously challenging. Placement in a least restrictive environment guarantees that these students are being stretched to capacity—and sometimes beyond. There is no such thing as a typical day for these atypical children.

Pause and consider the moment when these parents were told that their perfect little child, born with ten fingers, ten toes, and infinite possibility, actually has a pervasive, permanent, neurodevelopmental disability. For many parents of children with significant special needs, the diagnosis of a lifelong disability is akin to a death: It represents the sudden shattering of hopes, dreams, and legacy. Often, parents go through a lengthy and agonizing grief process that includes intense periods of denial, anger, self-blame, hopelessness, and depression, before they can begin to accept what is, as well as what may never be.

Just living with and raising a child on the spectrum day after day can be physically and emotionally debilitating. But despite that, these parents must kick into high gear, rallying on behalf of their child. Parents must quickly educate themselves about this exclusive society to which they have been appointed but never wanted to join. They must wend their way through serpentine systems to round up suitable services, squashing any vestiges of parental pride to shout out their child's challenges in search of help. Obtaining services is time-consuming, costly, and rarely well covered by medical insurance, so a heavy financial burden likely weighs on the family as well. All of this is in addition to attending to the everyday needs of a typical family, including those of the child's siblings who often get lost in the shuffle.

Just as you do with your students, be mindful of where the parents have been and meet them where they are.

Given these overwhelming and unrelenting circumstances, it's no wonder parents may seem highly anxious, depressed, or wary. Depending on where they are in their personal journey, some parents may get teary every time you introduce a new concern; others may flatly reject your interpretations because they simply cannot handle one more thing. Just as you do with your students, be mindful of where the parents have been and meet them where they are. In your journey together, remember that every accommodation and modification you provide highlights yet again for parents just how different their child is. As spectacularly successful as your sticker charts and behavior plans may be, they are, at best, bittersweet victories for these weary parents.

A Powerful Partnership

The world offers these kids—and their parents—a steady stream of

negative feedback, failure, impatience, and social rejection. In many cases, these kids are noticed *only* for their challenges and provocative behaviors.

So when you speak with parents, accentuate the positive. Lead with strengths, and if you can't find them, look harder. Praise students for their honesty; call them out for their reliability; commend their command of dates and time. Show parents that you see their child as a whole person—not simply an amalgam of challenges and disruptions. Let parents know that you value and appreciate their child's presence at school. This approach will not only warm the hearts of parents who have been struggling, but it may also allow them to let down their defenses a bit and bolster their ability to hear your concerns.

In these conversations, acknowledge that parents and educators bring different kinds of wisdom to the picture of a whole child. Parents are the historical and holistic experts: Their specialty is their own child. As teachers and administrators, our specialty is educating a classroom or school full of students. Show parents, early in the school year, that you value their wisdom by asking them about their child's interests, what kinds of things set their child off, and what can improve a situation. (For a sample family questionnaire, visit http://bit.ly/FamilyQuestionnaire.)

I always tell my son's teachers and school administrators up front that I see us as a team. I tell them in no uncertain terms that, even though I know my son best, I don't know him at school, so I welcome their perspectives. And I mean it! I also tell them that they don't know him at home, and so I hope they will welcome my perspectives, too.

Providing an opportunity for parents to share their wisdom not only gives you a leg up in your work, but also signals to parents that you respect them as partners on the bumpy road ahead. Join hands and hold on tight. Together, we can help our students climb out of the potholes, clamber over the obstacles, brush themselves off, and reach heights they—and even we—never thought possible. EL

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