

Hitting the Switch: ¡Sí se puede!

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On a cool fall afternoon in the Maple classroom, co-teachers Andrea and Stephanie stacked chairs, laminated family pictures, and organized the class library. Their K-1 class had left for the day, and Stephanie decided to shift the children's names on the job chart. As in many progressive schools, classroom jobs were an integral part of the daily routine in Maple. Each day the students eagerly walked into the classroom and checked what their responsibility would be. Jobs included wiping the classroom tables, counting how many children were present that day, and helping with lunch. Regardless of their specific job, the students took pride in and ownership of the classroom. The chart had 24 jobs displayed on a large board, with the students' names in alphabetical order. Students had started counting how many days it would be until they would have a turn at their favorite job. As Stephanie rotated the names, she realized who would have the job of class greeter at the upcoming Friday recital: Jason.¹

The class greeter's role is to announce the presence of everyone at morning meeting by singing their names. On the upcoming Friday, the greeter would kick off the first weekly recital of the school year by singing the names of the children before all students joined in singing to greet each teacher and parent in attendance. Afterward, each child would have a turn to stand in front of the audience and sing, recite a poem, tell a joke, or play an instrument. Jason's paraprofessional was ready to support him in playing the keyboard that morning for his individual recital, but the teachers felt unprepared to help him fulfill the role of class greeter. That job involved singing, and due to an acquired brain injury brought on by a rare disease, Jason had limited physical mobility and was unable to speak or sing.

Stephanie and Andrea felt baffled. Their deeply rooted belief that children of all abilities should be in inclusive classrooms was challenged. The emotions were so overwhelming that they considered doing something that went against their commitment and desire to be completely inclusive: they discussed changing Jason's job for that day.

After some reflection, they dismissed that option. They agreed that changing Jason's job would go against the values of inclusion that they had been promoting; inclusion was not something to be practiced only when it was convenient. They worked hard to create a community that accepted and supported all members and encouraged each student's growth. Jason should not have to conform to a narrow vision of what a greeter did. They, the

¹ Jason is a pseudonym.

community, had to figure out how to make Jason's role as the greeter work.

Background

Prior to the beginning of the school year, the authors of this paper—Stephanie and Andrea (Jason's teachers) and Sandra (Jason's mother)—wondered, mostly privately, if an inclusion class at Castle Bridge Elementary School—a public, dual-language school in Upper Manhattan—was the most appropriate first-grade placement for Jason. New York City public schools' recent special education reforms encouraged enrolling more students with complex special needs in neighborhood schools (New York City Department of Education, 2012), but the supports and systems for those students' full inclusion were still developing (Ford, 2015; Wall, 2014). All classes at Castle Bridge, which opened its doors in September of 2012, are inclusion classes. Students with individualized education plans (IEPs) are in every classroom, and inclusion is framed as part of the school's overall commitment to diversity and social justice.

We all believed in the power and promise of inclusion but had not ourselves ever seen an inclusion classroom with a child as medically involved as Jason. His illness, which had come on suddenly four years earlier, had caused severe motoric limitations, affecting Jason's ability to get his body to do what he wanted it to do. He used a manual wheelchair, pushed by an adult. He needed a nurse to accompany him throughout the school day. His communication strategies were varied and inconsistent, and our ability to understand his intentions was unreliable.

Jason's first year back in school after his illness was in a multigraded, self-contained class with six other students at another school. By moving into an inclusion class at Castle Bridge, he would be learning with 23 other children; some of them would have IEPs, but most of them would not. Including Jason was going to require thinking beyond our lived personal and professional experiences into new possibilities.

When we initially met several weeks before the first day of school, we did not focus on our doubts. Sandra and Matt (Jason's father) explained Jason's health history and current condition. Stephanie and Andrea asked questions about communicating with Jason and about his basic needs. We agreed that we would work in partnership and would make our best collective effort at creating a positive educational experience for all the children in the Maple classroom. We agreed that we needed to give this experiment some time before deciding whether or not it was working or workable. With hope

that our dreams of inclusion could be realized for children with support needs like Jason's, we took a collective leap of faith. During that initial meeting, we discussed our inability to fully assess Jason's comprehension since he could not produce consistent motoric responses to stimuli.

Prior to the onset of his illness, Jason was a precocious toddler with a vast vocabulary and a quick wit. He had met all developmental milestones early and was starting to read. Once he began recovering from a lengthy, critical phase of his illness, Jason evinced efforts at getting his body to move, but there was no way to know what he would say if he could coordinate all the muscles needed to speak. Unable to assess Jason's comprehension in any valid or reliable way, we agreed that the "least dangerous assumption" (Donnellan, 1984) was that Jason's comprehension was intact.

On Sandra's recommendation, Andrea and Stephanie read *Ghost Boy*, the memoir of Martin Pistorius who, due to an acquired brain injury, was locked in his body for 12 years (Pistorius, 2011). Before Pistorius could demonstrate his comprehension, his family and caregivers assumed he had little to no understanding of the world around him. His memoir served as an important point of reference, guiding us away from making assumptions about what someone can understand based solely on what they are able to express.²

We worked together to ensure that all areas of the classroom, arranged in learning centers designed for student access and movement, were also accessible to Jason. Before the start of the school year, Sandra and Jason visited the classroom to make sure that he could maneuver around project areas and would have a designated place during meeting time as well as that his chair could roll up under at least one classroom table so he could play and work alongside classmates. While we were preparing Jason and ourselves for the coming school year, the custodial staff was constructing an accessible bathroom stall. We discussed fire drill protocols and potential field trip challenges. We talked about communicating with parents and students about Jason's entry to the school and classroom community.

We all understood that special education could be contentious terrain. Schools are not typically designed for flexibility and adaptation, and children with special needs require additional support; in resource-strapped public systems, providing the necessary support can be a challenge. Practitioners fear litigious parents who do not appreciate the systemic obstacles to providing services, and parents fear disinterested and dismissive practitioners who do not appreciate the promise, potential, and rights

2 Subsequently, *Ghost Boy* was shared with the entire staff, as was *Out of My Mind*, a young adult novel about an 11-year-old girl with cerebral palsy who is unable to show what she knows due to motoric limitations (Draper, 2010).

of their children (Fertig, 2016; Ford, 2015). Pressures regarding assessment and accountability provide further disincentives for enrolling students with complex needs (Kanso, 2015; Lesch, 2012).

A series of anxiety-fueled, what-if questions kept Andrea and Stephanie up at night. What if the other children shunned Jason? What if he could not go on field trips? What if he had a medical emergency? What if the school's weekly swimming sessions in the fall and skating trips in the winter could not be adapted for him? What if parents questioned his placement in their child's class? What if his academic, emotional, and social needs were not met? What if we could never access his thoughts?

While we all wondered whether Jason would have friends, whether he would be able to participate in classroom activities, and whether project time and recess could be adapted into meaningful learning opportunities for Jason, Andrea took comfort in the thought that the children would be our teachers, and that we would follow their lead. We were embarking on something we had not yet seen ourselves—not as students, as parents, or as education professionals. We therefore strove to “[set] the stage for miracles” (Barrera & Kramer, 2009, p. 71), knowing that such miracles would require a high-functioning and dedicated team.

Sharing an ethos of ¡Sí se puede!

Stephanie and Andrea thought about the various ways Jason might be able to serve as class greeter. His Step-by-Step switch³ seemed like a possible tool. They knew that by hitting the switch, Jason could activate it to play prerecorded words, but they were not sure if it could hold 24 individual names. They felt strongly that the recorded voice should be that of a child around Jason's age (rather than of an adult). They sought the guidance of Jason's speech and occupational therapists. Both were eager to help. The speech therapist prepared the switch for the activity. The occupational therapist coached the nurse and paraprofessional in the best ways to support Jason's elbow and to place the switch so that Jason could use his arm muscles to activate it.

Including Jason required a strong team. The IEP from his prior school contained mandates for several daily services. We wanted to strike a balance between Jason's needs for multiple therapies and our desire that he learn alongside his classmates. While some therapies could be integrated into the classroom, others might be more beneficial in a pull-out setting. We agreed that we would neither follow the existing IEP nor make official changes to it until we had time to get a collective feel for how Jason was doing in the classroom. Our goals were to maximize the amount of time Jason could be in the

3 The Step-by-Step switch is a touch-activated, speech-generating assistive communication device.

classroom and to match the services he received to appropriate related classroom activities.

Our agreement not to focus on strict adherence to the existing IEP required trust between all team members. Jason's parents needed to trust that this was an opportunity to create the best possible way to provide Jason's services, and the school-based team had to trust that the parents would not sue them during this trial period. All team members had to trust the power of careful observation as a mechanism for making wiser decisions and constructing a better IEP.

This experimentation period was instrumental in successfully including Jason. For example, we initially tried having Jason's speech therapy as a push-in service during project time. While his classmates were playing at the water table or block station, Jason—surrounded by his nurse, paraprofessional, and speech therapist—was learning to use his communication device. Jason's nurse noticed that he would often cry during these sessions and hypothesized that his crying might indicate his desire to participate in project time with his peers. Stephanie and Andrea observed a session and asked the speech therapist to try scheduling her service for a different time of day. After the time and place of the speech therapy session were adjusted accordingly, Jason's demeanor changed dramatically, and he seemed much happier during both project time and speech therapy. We realized that pull-out speech sessions that didn't interfere with Jason's ability to participate in project time worked best for him. In addition, his paraprofessional carried over the skills she learned from the speech therapist into other curricular areas.

We have developed a collective ethos of *sí se puede*, a term that is often translated as “yes, we can” or “yes, it is possible.” *Sí se puede* is the motto of the United Farm Workers and connotes the possibility of overcoming obstacles in the pursuit of social justice and civil rights. For us, this phrase encapsulates each team member's commitment to overcoming both predictable and unforeseen impediments.

We enact our commitment to *sí se puede* when we approach some of the school's routine physical activities (scheduling OT for weekly swimming, ice-skating, and capoeira lessons), when we spontaneously take the children sledding after a snowstorm and shovel a path for Jason's wheelchair through the snow banks that block intersections after plowing, when we use only subway lines with accessible stations or arrange for accessible bus transportation when we go on field trips, when we carry Jason onto a wheelchair-inaccessible stage for the Spring concert, and when we design each new curricular unit by thinking through his participation.

At its essence, our ethos of *sí se puede* reflects our shared belief that we can collectively figure out the best way to ensure Jason's full inclusion in all school activities. All the team members—the speech, occupational, and physical therapists, vision teacher, classroom teachers, students, parents, nurse, and paraprofessional—have contributed. As Sandra says after every new creative innovation, “This is the *sí-se-puede-est* team of people I have ever met!”

Jason's team extends beyond the classroom. The principal and administrative support staff play critical roles in allowing for the creative and dynamic problem solving that enables Jason's full inclusion. For everything from creating purposeful, yet flexible, schedules to booking accessible buses when needed, we rely on dedicated support from the school leader and administrative team.

Fostering friendships

The speech therapist worked with two of Jason's classmates to ready the switch for Friday's recital. With great pride, they recorded each class member's name, effectively donating their voices to Jason. On the morning of the recital, the students and family members found a place to sit in or around the classroom's meeting space. The children fidgeted with pre-recital jitters as their grown-ups sent them encouraging looks. Andrea welcomed the children and their families and noted that one of the class jobs was that of greeter and that today that responsibility was Jason's. The children quieted quickly. Whatever nerves they may have had about their own recital performances faded into the background as they rose to their knees and inched closer to Jason. Their focus was on him.

As we prepared to welcome all of the children to our classroom, we worried about how things would go for Jason. From the first day of school, the children showed us that embracing Jason as their friend was easier for them than we had predicted. All classes at our school are multigraded; half of our class were returning students, and half were new. For the first half of the day, the whole class was together, decorating name tags and playing games to learn each other's names.

After we chanted all our names, we talked about how our classroom looked a little different than the previous year. We explained that we would call a “returning Maple” to take a “new Maple” on a tour around the classroom and talk about what we did in each area. One of the returning Maples had talked excitedly that morning about having seen Jason in the park over the summer. We decided to have her choose a new Maple first, secretly hoping she would pick Jason. She got up and immediately went to hold Jason's hand, just as we'd hoped. She then walked alongside him as his nurse pushed him around

the classroom in his wheelchair. At that moment we realized, with hope and relief, that the children would indeed be our teachers.

At noon the new Maples went home. We took this opportunity to open up a conversation with the returning Maples about Jason in his absence. We started by saying that perhaps they had noticed that a new Maple needed a wheelchair and invited their thoughts and questions. Hands went up. Children wanted to know why Jason needed a wheelchair and why he could not talk. We decided to continue the conversation the following day with the whole class when Jason was out at a doctor's appointment.

We explained that Jason had gotten sick, and that now his brain did not remember how to do some things like walk and talk. When one of the children suggested he was like a baby, we stated clearly that he was definitely not a baby. He was six years old, just like some of them. He could hear and understand everything we said. Just like them, he wanted to play, learn, and make friends in school. The conversation reached a beautiful conclusion when the student who gave Jason the tour stated, "We are all the same inside. We all have the same heart!"

It was important that the children knew that there would be time and space for more such conversations if they needed to have them. We told them to feel free to ask any questions as we got to know Jason better. We shared with them two books that Sandra lent to the classroom. They explained Jason's story in child-friendly language with beautiful photos. One was called *The Warrior* and the other *Jason's Superhero Year*. *The Warrior* has photos of Jason before he got sick as well as photos of him with tubes and bandages in the hospital. We worried about the children's reaction to some of the photos, but once again, they surprised us. They loved the books and looked at them often throughout the school year.

On the playground later that week, children from another class approached Jason and asked his name. A Maple classmate standing nearby smiled broadly and said, "His name is Jason, and he is *our* friend!" She then suggested they all play Ring Around the Rosie with Jason, and a few children quickly gathered around, making a circle and holding Jason's hands while his nurse pushed his wheelchair. These moments of budding friendships happened daily during the first weeks of school. Most of the time, the children initiated play with Jason, but the adults around him also facilitated friendships by inviting children to play tag with Jason, beginning conversations with him, and supporting the children's ideas for games in which Jason could participate. When children spoke about Jason, making a comment such as "I like his shirt," the staff made a point of redirecting the comment to him: "Don't tell me, tell Jason."

Time and again the children showed us that our fears that Jason would be socially isolated were unfounded. We had worried that no one would want to be Jason's line partner since they would have to take a different route to recess than the rest of the class so Jason could use the elevator. We therefore decided to assign line partners and change them biweekly. We soon found ourselves inundated with requests to be Jason's partner, and ultimately needed to set up a waitlist.

We also worried that when Jason cried and was unable to tell us why, the children would worry about him and feel as anxious and helpless as we did. Then one day when Jason cried, a classmate suggested that we sing to him. Although listening to *I've Got Peace Like a River* sung spontaneously by the entire class did not always help Jason with whatever was causing his tears, singing in solidarity with their friend certainly helped the class. Over time, the children became less distracted by Jason's crying, and although they maintained their compassion and concern, they also stayed focus on their own learning activities.

Every child in the Maple classroom loves and cares for Jason. They greet him with smiles and hugs in the mornings. When he is out sick, they ask about him and miss him. Just like any other child in our classroom, Jason has deeper connections with some children than with others. There are five children in particular who have formed strong bonds with him, enjoy reading books with him, and choose him to act in their stories—the ultimate symbol of close friendship in our classroom. Jason not only has friends, he has best friends. Tears welled up in our eyes when we overheard one of Jason's best friends tell him, "I wish I had a wheelchair so we could sit in our wheelchairs together."

Bringing inclusion home

Jason's paraprofessional held his elbow steady as the OT had shown her, while his nurse secured the Step-by-Step switch within his reach on the wheelchair lap tray. Jason raised his arm and hit the switch. Hearing his friend's prerecorded voice announce a name, Jason's face lit up. He raised his hand a second time to greet another classmate. A father smiled warmly as he heard his son's name.

We agreed over the summer that we would introduce Jason to classroom parents during the first week of school. We wanted to support them in talking with their children about any questions or concerns that a classmate who cannot walk or talk might elicit. Sandra worried that other parents would question Jason's enrollment in this class, given the intensity of his support needs.

During the first week of school, we sent home the following letter:

Dear families,

We have had a beautiful time with the Maples these three days! We have worked on learning each other's names, and on establishing the routines and expectations in the classroom. We are just beginning to get to know the children, but we are already falling in love with each one. We cannot wait to have our family interviews starting next week to hear more about them from you. We have 24 amazing children, each wonderful and unique. Every child in our classroom is special. But we thought it is important for you to learn a little more about Jason, one of our new Maples, as many of your children have asked questions about him. Here is a note about Jason from his mom, Sandra, in language that your children can understand if they have questions:

When Jason was almost three years old he became very ill and stayed in the hospital for over a year. When he got sick it made it hard for him to walk and talk and eat food by mouth. For a long time he needed machines to keep him safe, but now he is able to go to school using his wheelchair and he doesn't need the machines anymore, except for a small pump that gives him water when he is thirsty. The pump hangs in a backpack on his wheelchair and gives him water through a tube that goes right into his tummy. While he is still not able to talk or walk, he does understand what is being said and can stand with the help of a grown-up. He also needs a grown-up to help him in the bathroom, and to feed him food that is mixed in a blender since right now he cannot feed himself. He likes to eat pureed carrots, chicken, tuna salad, sweet potatoes, chocolate pudding, applesauce and lots of other foods too.

He will turn seven in December and he really likes when people talk to him like they talk to other children his age. He loves music and being outside and listening to other kids talk and play and tell jokes. He is really good at teaching people about themselves, keeping secrets, and making people hopeful and happy. He is very, very strong.

As he continues to heal, he sometimes has movements he cannot fully control, he sometimes cries and we are not sure why, or makes sounds that we can't understand. Sometimes he laughs at silly thoughts he is having, but he can't tell us what they are. He responds well to love, to kindness, to patience with the time it takes him to get his body to do what he wants it to do,

and to respect for who he is and all that he has been through. He is very excited to become part of the Castle Bridge community!

The Maples have warmly welcomed Jason into our classroom community. Although they have been curious about why he needs a wheelchair and why he cannot talk (and we have been open to their questions and have explained) they have also seen him as another new friend and have been very happy to greet him, talk, play, and share with him.

After the letter was distributed, several parents approached Sandra. Some shared that Jason's presence in the Maple classroom allowed them to envision how an inclusion classroom might work for their own children with special needs who were currently enrolled in private, specialized schools or who were not yet school age. Several parents said their children now assess the wheelchair accessibility of every place they go. "That boy has done more for the children in our school than the school could ever possibly do for him," one parent said. To Sandra's surprise, not a single parent questioned why Jason was in the Maple class. Early communication with all families proved invaluable in creating an inclusive classroom community.

Fostering social-emotional and academic learning

Jason's smile grew as his arm lowered and the switch broadcast the last of his classmates' names. "He wants to be here—it's not just our dream," Andrea thought, feeling great relief. Stephanie surmised, "Not only is he a member of this community, he can contribute to it. He can do his job." Sandra's eyes were brimming, "He is happy. He has the support of a collaborative, creative team of adults and the respect and love of his friends." The learning opportunities for Jason, the rest of the class, and all the grown-ups involved were limitless.

In our classroom, learning centers around play. One of the fundamental components of our curriculum is daily project time, during which students work in the learning centers, exploring blocks, a sensory table, art materials, and more. Project time is when we see Jason make the most progress; his hand function, eye contact, and focus all improve while he engages with his peers. Most first graders love to play with their peers and thrive when given opportunities to learn new skills. Jason is no different. We therefore focus on maximizing his opportunities to be an active participant in classroom activities.

Making our curriculum accessible to Jason demands creativity and collaboration. While we have invented ways to include him in all aspects of our educational program, approaching his literacy and

math development has required the most thought. Without a reliable way to communicate with Jason, how can we assess his math and reading skills and comprehension? His parents reported that prior to his illness, he had full letter and sound recognition and several sight words and also understood the basic concept of addition. Had he maintained that knowledge through the illness? Had he built new knowledge with the help of his parents and previous teachers? Without a consistent communication system, it would be impossible to know.

Our approach relies on experimentation. We look carefully at how Jason attends to text when we conference with him. We start each conference with books using large print, telling him that we know they might be easy for him but that afterward we can move on to reading about superheroes or Star Wars. We have noticed that he attends to the high-interest books more readily (as do several of his classmates), but whether he is actually following the text and making meaning of it remains uncertain.

In the meantime, in speech therapy he has advanced from the single switch to a Tobii communication device with which he now reliably answers math questions, identifies sight words, and demonstrates comprehension. He has learned to listen quietly during read-alouds, and over time we have seen him attend to text more regularly during reading conferences. Our approach to his academic learning is a constant work in progress, relying on patience, careful observation, and creative responses.

His social-emotional learning has also required new thinking. Over time, we have realized that Jason is more capable of making choices about his behavior than we originally thought. When we realized he was craftily getting away with behaviors that we would not allow from others, we spoke firmly with him about our expectations and started to see improvement. Jason, like all other children, could and should be held to expectations for his behavior.

Jason's inclusion in our class enhances the academic and social-emotional learning of his classmates. Including him opens up new awareness of the world we live in. It has also given students opportunities to engage in creative problem solving to enable Jason's inclusion. Our students are learning to relate to the world not in terms of what works for them alone, but in terms of what works for everyone.

Final Thoughts

We are certain that the experience of including Jason in the Maple class has benefitted the lives of all our students. We have witnessed many magical moments of friendship and mutual benefit. We predict

that our students will always know that strong bonds can be built across differences and will be more likely to approach people with disabilities rather than either stare at them or look away.

Initially we thought the value of inclusion for Jason's classmates would be obvious, but we wondered whether Jason would benefit as much as his peers. His determination to do his classroom jobs, his excitement in choosing an area at project time, his huge smile while he swims and skates in a apparatus constructed by his OT (¡sí se puede!), and his happiness as Sandra gets him dressed for school each morning signal his love of being in the Maple class. He has shown wonderful progress socially and academically as well as in his physical recovery. As Sandra articulates it, after several intensely medicalized years during Jason's early life, inclusion in the Maple classroom has given him his childhood back.

Jason and his friends have taught us that given the right support and orientation, children with vast differences can learn and play together, are quick to embrace one another, and recognize the intrinsic value of each other's humanness beyond traditional definitions of ability. They do not focus on what their friends cannot do. They do not see each other "as a problem faced with a complex of problems" (Marty, 2007, p. 1). This experience has helped us see all our students as "a mystery surrounded by mystery" (Marty, 2007, p. 1). The habits of mind we have developed to include Jason extend to our work with all of our students, both with and without special needs.

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Sandra J. Stein is Benny's mom. Prior to his illness she was CEO of the NYC Leadership Academy and Associate Professor of Education at Baruch College School of Public Affairs. She holds a PhD in Education Administration and Policy Analysis and an MA in Political Science and International and Comparative Education from Stanford University. Past publications include *The Culture of Education Policy* (Teachers College Press, 2004) and essays in the *New York Times*, the *Atlantic*, and the *Washington Post*.