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6. THE UNEXPECTED

*What I Didn't Know I Had to Do as a Severe and
Profound Intellectual Delay Teacher*

Like many new teachers, my first year teaching was an adventure that I was ready for before I was even done with my student teaching. I just knew that I was good at teaching because my professors had consistently given me great reviews during my student teaching observations. My ego was inflated going into my first year teaching because of those glowing reviews. I would not admit to anyone that I was scared to take on my mild intellectual delay classroom because it was not what I had been given extensive training in, but it was what I wanted to teach. I was so headstrong as a first year teacher; come hell or high water, I was going to teach students with intellectual delays and be good at doing it.

NEW SKILLS IN MY FIRST YEAR

The first class I had was a sweet fourth and fifth grade mild intellectual delay class. I had no clue what I was doing. That was very apparent the first day when my student with spina bifida walked in. I had no formal training in how to deal with students' physical and health impairments. I recognized that I had no knowledge of any specific disability. I was going to have to learn as much as I could and quickly! As my new students continued to file into the room, I felt that I was way in over my head.

Later that morning, the county nurse came into my classroom to meet me. I found myself fumbling through the IEPs for my students, wondering why the nurse was telling me that I had a student with nursing services. I did not recall seeing that in any of my IEPs. I felt so dumb that I missed that bit of information. During the brief meeting with the nurse, I was informed that I was going to have to learn to catheterize one of my young female students. In my mind, I was thinking, "Wait, you want me to do what?" Upon the nurse's return that afternoon, I had to watch the process of catheterizing this student. I was mortified for this girl and myself. How could she possibly be ok with her teacher watching such an intimate procedure?

At the end of the day, I sat down at my desk exhausted, still incredibly nervous that I would screw up somehow, and worried that I was going to be expected to meet the medical need of this child. My principal sent me an email to meet with her in the morning regarding this child. In the end, I was not responsible for catheterizing this

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particular student. I was relieved that I was not responsible for that service on the child's IEP but wondered if or when I would have such demands made of me again in my teaching career.

IT WAS LIKE BEING A NEW TEACHER AGAIN, EXCITING!

Entering into my third year teaching, I found myself in a new school, in a new special education setting, and on a new grade level. Earlier that year, I very excitedly took a position in a severe and profound intellectual delay classroom on the high school level that would start in August. After two years in elementary school, I was ready to move up to working with older students. I had this idea that I was again going to be a great teacher making miracles happen for these students every day. What I did not know, but learned quickly, was that my students were going to make gains at a snail's pace. At least, it felt that way, but I learned to celebrate the small things in a big way every time they did have those gains. If it meant that, from day to day, they were not going to perform the same skill, I could be fine with that. On the days that they did something amazing, I danced around my classroom like a crazy woman, letting my students know that I loved when they did so well.

This class challenged me in profound ways and opened my eyes to so many experiences that I never imagined I would have. If I had been asked as a student teacher whether I would do some of the things that this class required of me, I would have laughed and said no. At the start of my career, I was positive that the SID/PID setting was not for me. Never would I have thought that a group of seven students over the course of three years would change my life and solidify my passion for changing the lives of students with disabilities. This was what I wanted to do from the beginning of my career. I was in a place to make a big difference in the lives of my students. I would have never guessed that they would have made such a large impact on me.

My class started off small with four students. Two of my students were in wheelchairs. None of them were potty trained, only a couple could feed themselves, one student – Kendra – had a severe seizure disorder, that same student had to be catheterized, and one student – Dean – had Fraser syndrome and was born without eyeballs. All of my students were non-verbal, which meant that they could not always communicate their needs to me. This class was a whole new learning curve because I spent the first few weeks trying to learn body language and signals. I never had to guess before because my students in my previous jobs could communicate with me. I felt like a brand new teacher all over.

During the first week, I had to learn how to change a diaper on adult-sized individuals who would not hold still. Thanks to babysitting as a teenager, I knew how to change a diaper, but the rules changed when the person to whom the new diaper was being applied did not hold still and the diaper ended up crooked and not covering all essential parts, or heaven forbid the diaper was not on tight enough and would not stay up! Changing adults was not like changing a baby. It was much

harder and a talent that I had to learn. Then there was also learning to catheterize Kendra student. As a young 24-year-old teacher, I was still highly embarrassed to have to do something that seemed more personal than just whipping someone's rear end. I was slightly more prepared having just received an *A* in the medical procedures class during the course of my master's program in multiple and severe disabilities, but it still did not prepare me to actually perform the procedure. Nor did it help me to feel any less embarrassed Kendra. I would not let the school nurse leave my side for two weeks while in the learning process. Several times, she had to finish the procedure for me because I could not get the tube in the correct spot. There was slight relief knowing that I was, at least, familiar with the female anatomy, being a woman myself. I just prayed that I would never have a young man who required this type of care step in my room. I was learning that I was going to be in a more intimate care giving setting as a SID/PID teacher than I first thought. I was not sure I was ready, but I was sure that I was in the classroom that was meant for me.

Diapering a student was not all that I learned. I had to puree food to the correct consistency so that my student Paul would not choke. I had to make drinks such as water and juice thicker because Kendra would aspirate on liquids. It was scary knowing that my students had a higher choking risk. In fact, it happened one day during my second year in this classroom. My student had just learned to use a fork to feed herself, and Kendra stabbed too many chicken nugget pieces on her fork. Before I could think about what I was going to do, I was pulling a very low tone, floppy, and over 100-pound student out of her wheelchair and attempting the Heimlich maneuver. I am pretty sure that, to a bystander, it would have looked like I was shaking this child. She finally coughed up the chicken nuggets. I was so shaken that I collapsed on the floor, still holding the child, shaking like a leaf from the sudden rush to action adrenalin, while her pulse oximeter beeped because her oxygen level had dropped below 90. This was not the first or the last emergency that I would have to deal with in this classroom. However, it was one that made me realize that I could not panic in an emergency. I just needed to react fast enough to ensure my students' safety. During times like that, I felt inadequately prepared for what was at hand. There were many sleepless nights while working in this classroom. I would worry about the medical frailties of my students and hope that I was meeting all of their needs both physically and educationally.

Monitoring breakfast and lunch was a task that required a good hour and a half for each meal to be completed. It was a difficult task, as I felt that I needed hand upon hands to get through it. I was managing more than just table manners and behavior. With the help of my paraprofessional, we had to puree food, to thicken liquids, and to cut everything up. We both sat with the students at the table because Molly felt compelled to eat off other students' plates, Kelly liked to spit food across the table, and then we had Paul, Kendra, and Dean, who were unable to feed themselves. Sometimes it was all that I could do to sit down and put food in my mouth. My lunch was on the fly when I could fit it in between lunchtime and the end of the day.

At first, I felt like my instructional time was so minimal due to feeding and diapering. It took me a while to feel like I was maximizing the small amount of time that I could do whole group and then I would work with individual students. I was always second-guessing whether I was providing my students adequate instruction. As the year progressed, I was able to bring in general education students as partners for my students. We worked on reading, math, and social skills. My students made the greatest gains in their abilities from those partnerships.

During my second year, my class and I gained students. Mickey was semi-potty trained, and Ellen had the ability to be potty trained but preferred to use her diaper, so I had to learn how to trip train a student. I thought since I was previously an elementary special education teacher that I would have no problems trip training Ellen. I was wrong. The first day, she pooped in her diaper and proceeded to wipe it on the walls in our classroom bathroom. It felt like teacher-1, student-0. The next day, I missed every single cue for her bathroom schedule, and she peed in her diaper three times. She thought that it was funny. That day was student-1, teacher-1. Finally, the next day, I was smart; I brought out the positive reinforcement to get her to pee in the toilet like a parent would do with a little kid. Stickers on the sticker chart were the key. She loved to put one on her chart every time she peed. I was blown away at the skills that I was picking up as new students were presenting me with new challenges.

This class challenged me in ways that I never thought were possible. I was a pro at problem solving on the fly. When Kendra wiggled her way out of her chest straps on her wheelchair and leaned forward to get out of work, I rigged those straps so that she could not get them loose and had no choice but to sit up in proper positioning. Another time, I had a wheelchair wheel break as we were going out to the bus. I pull the wheel off and duct-taped the spoke back together and put in a call to the repairman. The child safely rode home on the bus, and the repairman was in my classroom the next day with a spare wheel. I had extra clothes on hand at all times just in case one of my students needed a change. At any given time, I looked like a pack animal because I always wanted to make sure that I was prepared for any number of issues to occur. It took me a year to get to that point, but as issues arose, I would just add to my preparedness kit. When we went out on community-based instruction, I figured out a way for my student with Fraser syndrome to carry the bulletins that we picked up at a local church. Never in my previous years teaching did I have to employ such ingenuity to make things work for my students.

Halfway through that second year, I picked up a fifth student. Don was the most difficult student I had ever dealt with. He was a paraplegic due to a car accident but was born with an intellectual delay. He remembered what his life was like to walk and, as a result, grew up as a very frustrated young man with no communication skills. Upon his arrival, I learned that he was catheterized, and the fear of catheterizing a male student set in. Watching the nurse insert the catheter was even more mortifying than having to perform it on Kendra. Don was 20 at the time, and I had just turned

25. I had a hard time fathoming the fact that he was a man and I was a young woman. The age should not have mattered, but to me, it did. I expressed my concern about catheterizing a male student to my principal and was read state law, which said that the clean intermittent catheterization was not a medical procedure and could be performed by a layperson. I was just going to have to deal with the uncomfortable feeling and do it. I was not sure where I was going to find the inner strength to that procedure, but I did. I made it through my first week and my second and my third before the nurse dubbed me trained.

The next year, I added two more students, which put me up to seven. That year, I was expected to learn how to feed John using a tube-feeding pump that circulated for two hours. It was by far the easiest skill for me to learn, except for the first day I was left to my own trained devices, and I accidentally did the worst thing that I could have done to this student. I accidentally hit the tube as it was hanging from the pump, and I pulled out the student's mickey button, the button where the tube is connected that creates a direct line to the student's stomach. I ended up with formula and stomach fluid all over the front of me. I never wanted my students to feel that I was ever grossed out by anything I had to do to care for them. I always did my best to hide it, but this time I could not help it. I started to gag as stomach fluid came out. It was like a sudden eruption of Old Faithful at Yellowstone; as soon as it happened, it stopped. The student's mother came and took my student to the doctor to have the button replaced, and the balloon at the end reinflated. She assured me that what I had done, she had done several times since the feeding tube was put into place.

Those students really showed me what I was made of as a teacher. I learned how much stress I could handle and how much love I had to give, which was an endless amount. I always talked with my colleagues about how great my students were and about getting them prepared for wherever they would go after high school. I was always looking to the future of their growth while enjoying the time that I had them in my class. I knew that my students were medically fragile and that sometimes their lives hung in the balance. They were sick more often than regular students, and as a result, I developed a very strong immune system. I never realized how low their immune systems were until Dean got sick my third year working with him. That year, I learned the hardest lesson I would ever learn in that classroom.

DEALING WITH HEARTBREAK

My third year in my classroom, I felt the most at ease. I gained students mid-year, but I felt like I was prepared for all manner of possibilities that teaching SID/PID could entail. I was getting into a groove of feeding, changing, and teaching. I could get through that cycle twice in a day, and I was proud of that personal accomplishment. I could tell when I would need to change or reposition my students in wheelchairs. I knew when my students were happy or sad. I also found ways to communicate with them that made it easier for me to know when they needed something. I had

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behavior under control for the most part, with the occasional outburst every now and then. However, I never thought that I would have to deal with the deterioration that students with medical issues go through in their lives.

Within the first two weeks of school, Dean – who had Fraser syndrome – ended up in the hospital with pneumonia. He was out for a few weeks, and upon his return, we celebrated and welcomed him back. We had a party complete with cake and ice cream because that student loved his desserts. All was wonderful for a few more weeks after his return. He was the same incredibly smart and sweet child before he ended up in the hospital with one major difference; he was no longer comfortable in his wheelchair. He spent several days in pain no matter where I positioned him. I could not get the child to eat or drink. Both his mother and I were very concerned about what was going on with him. The doctor prescribed the student some pretty tough painkillers to make him comfortable, and it worked. I was relieved because I no longer felt helpless. This student was able to learn and attend to lessons just like he has before. However, I did not realize that this was not the end of his struggles that year.

In early October, this student was rushed into my classroom off the bus, and he was blue. It was very clear to me that he was in some major distress and that he needed to get to the emergency room quickly. Typically, there are protocols in a school building before dialling 911, but I skipped that. I did not care at that point if I would get my wrists slapped. I needed to get this child to the hospital. When I was off the phone and knew the ambulance was on its way, I notified my administration. They all came running, and I was barking orders at everyone to clear the rest of my students out of the room and to give Dean, who was in massive distress, space. I called his mother at the school where she worked and could not manage niceties on the phone with the school secretary. I simply said I needed Pam, Dean's mother, and it is an emergency. Pam answered the phone and my response was, "Your son is not OK, and we are heading to the children's hospital in Atlanta."

Those were the worst words to ever come out of my mouth. Never would I have thought as a teacher that I would have to deliver such a blow to a parent. There was nothing that I could do to comfort Dean or his mother. As I climbed in the back of the ambulance with Dean, I choked back tears, knowing that crying would do nothing to help and that the paramedics needed me to provide as much medical information for him as possible. That was not the last time that this situation would happen. In the course of the year, I made one more ambulance trip to the hospital with this student. It was several months later.

I spent much of my time trying to make Dean comfortable and happy as I watched him start to deteriorate physically. I still remember the last day I held him. We sat on the couch in my room, and I read him a book by his favorite author. For the first time in months, he was still, calm, and comfortable. Three days later, on the first day of spring break at 5:30 in the morning, his sister called me to tell me that he had died in his sleep. I was not able to process this information right away. It hit me an hour later that my student was gone. I had no clue what motions to go through when it

came to informing administration at the school. I called the only assistant principal who I knew was in town. I could not fight back the tears as I spoke with him. Word spread quickly to my colleagues, and I spent most of the day on the phone answering a number of questions.

I had spring break to deal with the grief that I felt, and then it was back on Monday to a seemingly empty classroom. I had to figure out what to tell my other students. I was not sure that they would understand what happened. I had one student that had delayed echolalia, and I had to tell her something that would not hurt my heart, as she was bound to repeat it multiple times a day for the rest of the year. I left the school the same year Dean died.

I had served my time in that classroom and felt comfortable making the decision to leave for a new classroom. I knew that my life and the way that I viewed teaching had changed. I was more open, kind, and loving. I learned that I never knew what my students would throw at me in the course of the day, but I also learned that I was strong enough to handle anything.

While my heart still breaks for the loss of such a young life, I know that my other students are doing well. I have touched base with parents, and this year, I can proudly say that my students whom I taught all three years are graduating in May of this school year. Their lives are still fragile, and they still get sick often, but they will live full lives because I worked to help them do that. I loved the challenge and would gladly do it again if the opportunity arose, but this time I would go in much wiser and smarter. I would utilize the people I work with in a more efficient way to help manage the physical needs of the students. I know how to communicate with non-verbal students better because I learned that they have their own mode of communication. I am proud to say that I am a better teacher and person for having had the amazing opportunity to work with that class.