

Widener University Delaware Law School

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SUFFERING FROM

Robert L. Hayman, Jr.*

Miss Nancy's pre-school class went outside for recess on every day that the weather allowed. To begin each recess, the class "leader" for the day—an honor that rotated among all the students—rang a bell at Miss Nancy's command, and assumed a position by the classroom door. The rest of the class lined up behind the leader, and waited for Miss Nancy's determination that they were sufficiently quiet and still to be permitted outside. Miss Nancy thereupon opened the door, and the kids filed out to the playground. After twenty minutes, Miss Nancy would instruct the leader to ring the bell, and the entire process would be repeated in reverse. This was the routine, and Miss Nancy had followed it faithfully for more than thirty years.

Caleb's mom was visiting the school on one of the relatively rare days that her son was selected to be the leader. Caleb's parents were aware of the fact that he was leader less often than other kids; they didn't know whether that was merely coincidence, or whether it reflected Miss Nancy's assessment of Caleb's leadership skills. This latter possibility disturbed them—it seemed harsh to judge a four-year-old that way, especially *their* four year-old—but they didn't raise it with Miss Nancy because, frankly, Miss Nancy terrified them. On this score, they were not alone: Miss Nancy scared all the parents, way more than she scared the kids.

And especially way more than she scared Caleb. This became evident on the day Caleb's mom watched her little leader from a second floor window of the school. The kids wandered about the playground kicking around a ball, or playing pretend people, or in the case of her son, searching for bugs on the asphalt's perimeter. Caleb's mom saw Miss Nancy summon Caleb, and hand him the bell, and his mom watched Caleb walk dutifully to the entrance door to the school. He must have rung the bell—his mom could see him, but not hear him—because the other kids lined up behind him, under Miss Nancy's watchful eye. Caleb's mom felt proud.

She was confused a bit when Caleb started swinging his arm wildly. Soon, the bell was ringing loud enough that she could hear it from inside, and the look on Miss Nancy's face confirmed that this was not part of the plan. And it certainly was not part of the plan when Caleb began running around the playground, grinning from ear to ear, all the while ringing the bell with manic delight. Most of the kids were following him, laughing hysterically; a handful stayed in their spots, staring wide-eyed at their classmates, or looking to Miss Nancy for guidance. Caleb's mom covered her mouth as she watched the line of kids snake around the playground with Caleb at the head; she didn't know whether to laugh or cry.

The rebellion ended quickly. Miss Nancy called for the bell, and Caleb surrendered it with a smile. The kids filed back into the school.

It was not out of character for Caleb. People progress through stages of moral development, and kids generally pass through their own distinct stages of

* Professor of Law, Widener University School of Law. Thanks to Nancy for inviting and encouraging me; thanks to Dr. Borin, Ms. Casey, Aunt Michal and everyone else who saw the joy and the promise; and thanks—and all my love—to Alice and Caleb.

development with respect to rules. Or so it is said. Caleb's parents had learned otherwise; in their experience, kids didn't generally pass through distinct stages of development, because kids didn't *generally* do anything at all; wasn't that, after all, one of the truly wonderful things about kids? In Caleb's case, his own unique approach to moral progression—at least as it related to the subject of rules—was to limit himself to a single stage—call it the “what? me worry?” stage. He decided early on that people should be nice to other people, and not be nasty to other people, but he didn't imagine this to be a rule, “golden” or otherwise. Because rules, for him, genuinely were made to be broken, which is to say that rules had absolutely no good reason for being, beyond the joy that resulted from their occasional disregard. And so, from an early age, he would ignore inconvenient rules, which tended to be, after all, indeterminate, manipulable, incoherent, and repressive, or, as he was apt to put it, “dumb.”

Caleb's parents had learned to accept this of their son. Miss Nancy, alas, was unlikely to be so accommodating. And so it was with genuine trepidation that Caleb's mom went to the classroom to pick him up at the end of the school day. Miss Nancy greeted her at the door.

“I was watching recess,” Caleb's mom said.

Miss Nancy smiled, and tried to stifle a gentle laugh. “Did you see our Pied Piper?” she asked.

“I did,” Caleb's mom replied, and both women smiled down at the little rebel, who was oblivious to their conversation, probably lost in daydreams of new shenanigans.

“I'll see you tomorrow,” Miss Nancy said, and Caleb's mom knew clearly why everyone who was scared of Miss Nancy, also loved her at the same time.

But this is not the “happily ever after” ending to the story. A year later, at the same school, Caleb's parents were meeting with his kindergarten teacher, and at the same time with his “support team,” and they were all urging an “educational assessment” of the boy, because, they thought, he was too distractible, and made too many bad choices, and really was not performing the way that he should. His parents were oblivious to the writing on the wall, so they engaged the educational psychologist recommended by the school, and the educational psychologist gathered reports from Caleb's teachers and his parents, and administered three hours of tests to the just-turned-six year-old boy, and a week later, the parents were meeting with the psychologist, who duly informed them of his findings. Caleb had done well on some parts of the test—his sensitivity to social situations, as measured by his “social vocabulary,” was in the ninety-ninth percentile—but on other parts he really struggled, and it was an effort at times to keep him engaged, and so what they were looking at, he thought, was an attention deficit, and hyperactivity, and some social phobia, and also, it seemed, Caleb was suffering from some quite irrational anxieties. Therapy was in order, and some social skills training, and a medical evaluation to see if Caleb was a good candidate for medication. As for the best educational program for him—the point, his parents had foolishly thought, of the whole ordeal—well, that was a bit hard to say.

The meeting was a surreal experience for Caleb's parents, with multiple layers of dissonance. The biggest disconnect was in this image of their son: he

was a sweet, sensitive, bright kid, with an incredible sense of humor and a nearly omnipresent smile. He had always seemed, in a word, happy, and it was hard to believe that he was really “suffering from” anything. But maybe they were just in denial; maybe they just couldn’t see. For the rest of that day the two of them went over it—and over and over it—separately and together, as they would for many months to come.

That night, Caleb couldn’t sleep. He didn’t want to go to school the next morning, and after school, he seemed irritable. More sleepless nights followed, for Caleb and his parents. And his parents began to notice how often Caleb seemed distracted, and how often they had to repeat things, and had he always been this rambunctious? and this loud? and this, well, annoying?

* * * * *

As a kid, I am told, I was “painfully shy” (now I have matured; I am now “pathologically shy”). I was eleven when my mom got remarried, and we moved to the suburbs and I went to a new school. At my new school, they grouped kids through what I now know as “academic tracking”: the smart kids were in put Section A, the less smart kids in Section B, and on through sections C and D. I was assigned to Section B, and I did not like it. In Section B we did current events, and mostly that meant *discussing* current events, and that required talking, and I could not talk. During the discussions I would sit quietly, usually drawing, and when I was called on, I would stare at my desk, and draw faster or harder. I had lots of meetings with teachers and principals, and the conversations were mostly the same: “yes I knew it was important to participate,” “no I didn’t want to be rude,” and at one meeting I recall one principal-type person asking another principal-type person if I was “retarded.” I knew that word—in my old neighborhood we used it freely as an insult—but its actual meaning was a mystery, and it was jarring to hear it coming from the mouth of an adult.

After one of these meetings I was transferred to Section C, which I think maybe was supposed to be a punishment, but I loved Section C. In section C all we had to do was draw—in history we drew historical figures, in science we drew planets, in math we turned numbers into animals—and we never had to actually know anything, and best of all we never had to talk. In a class just before Thanksgiving our assignment was to draw a picture of Pocahontas, and I knew Pocohontas from my old school, but none of the boys at my table—in section C we didn’t have individual desks, we sat at sex-segregated tables—none of the boys at my table knew Pocohontas, and they drew pictures of a very fierce and very male Indian warrior, which certainly would have made Captain John Smith’s story a more interesting one, but is, as far as I know, unsupported by the historical record. But my mom didn’t want me in Section C, and I guess she complained a lot, and after a little while I got moved to Section A. In Section A we had individual desks, and we also had teaching assistants, including one named Miss Zavishlok, on whom I very much had a crush, and she helped me to talk and I started to do okay in school.

At some point I learned the meaning of “retarded,” and I would wonder from time to time what would have happened if one of the principals had decided

that I was retarded, and I was always comforted by the knowledge that eventually they would have taken me to a doctor or something, and seen that I was not.

I started to learn better—that is, learn more about “retarded”—about fifteen years later. I was working as a Legal Aid attorney in St. Joseph, Missouri, and I got a case involving a young couple whose little boy was taken from them by the state when he was just four days old—still in the hospital with his mother, when the local juvenile officer physically seized him and put him in foster care. His parents, James and Louise, were mentally retarded, and everyone assumed that mentally retarded people can’t take care of children. It’s hard to disprove that assumption in four days—it’s hard to disprove that assumption in a lifetime—and so James and Louise, loving, caring parents, lost their little boy. I have a son of my own now, and I can more fully appreciate the agony they must have endured: I’d much sooner lose my life than my son. But back then, all I knew was what I saw: that they were a little angry, and a little scared, but mostly they were really sad.

I got the petition from the juvenile office a week later; the sole allegation was that the parents were “suffering from mental retardation.” What a phrase—“suffering from mental retardation”—and perfectly apt, though not at all in the way its authors intended. The juvenile officer imagined that James and Louise were afflicted with some disorder or disease; that they had come to us—from God, from nature—stamped “defective.” And at the start, I thought the same sort of thing, too. The same conceit that allowed me to believe that I was demonstrably not “retarded” led me to acknowledge that maybe James and Louise *were*. And so when I first got that petition, and started working on their case, the only way to win, I thought, was to prove that James and Louise demonstrably were not retarded. And then I got to know them. And I learned that wasn’t what it was about at all.

Of course, what the juvenile officer didn’t see—what I hadn’t seen—was that James and Louise were “mentally retarded” because we called them that, and the great bulk of the obstacles and limitations they encountered, and all the oppression, was the result of *our* decisions. The classes they could not attend, the jobs they could not hold, the places they could not live, the son they could not raise—we did that. And so I finally saw that the real issue in this case was not whether we had some reason—good, bad, or indifferent—for calling these parents “mentally retarded,” the real issue was whether these parents, because of what we chose to call them, should be made to suffer. Why, that is, must they “suffer from” this mental retardation?

I have learned to be wary of this phrase—“suffering from”—of what it generally connotes, and frequently portends.

A couple years ago, I came across the story of Jake Porter, a seventeen year old member of the Northwest High football team in McDermott, Ohio. Although he practiced with the team every day for three years, he had made only one brief appearance on the field during a game, until October 2002.

Jake Porter has chromosomal fragile X syndrome, a disorder that is a common cause of mental retardation. Jake has significant cognitive limitations: he cannot read, or write, and only recently learned how to tie his shoes (the captain of the 2001 team taught him how). Those limitations have not affected

his love for football, or his determination to help his team. And so for three years, Jake Porter practiced the game he loved, and worked for the team he adored.

On a Friday night in October, Northwest was enduring a 42-0 beating at the hands of Waverly High School. In the closing seconds of the game, Northwest coach Dave Frantz sent Jake into the huddle; the call was for Jake to receive a handoff and immediately kneel down—a play that Jake and the team had practiced repeatedly. Acting out of an abundance of caution, Frantz called a timeout to explain the play to the opposing coach, Waverly's Derek Dewitt. An animated conversation followed; it was clear that the coaches were not in agreement. The discussion ended, the two coaches met briefly with their respective huddles, and returned to the sidelines.

When play resumed, the Northwest quarterback handed the ball off to Jake Porter. Jake started to take a knee, just as he had in practice so many times. But his teammates stopped him; they pointed toward the opposing end zone and urged him to run. The Waverly defenders cleared a path; some joined in pointing the way. Jake Porter hugged the ball, and raced for the end zone.

For forty-nine yards he ran. Players on both teams ran behind him, cheering him on. In the stands, many parents and classmates roared their approval; many others cried; some did both.

Jake Porter scored a touchdown. The final score was 42-6. Interviewed after the game, a beaming Jake Porter said, "We won."

Jake Porter's touchdown may illustrate several different propositions. On a cynical reading, it may show the willingness of folks to accommodate people with disabilities when it does not entail much cost. On a more sanguine reading, one I choose to embrace, it may illustrate the triumph of community, and of inclusive and integrative ideals.¹ But there's a really harsh reading in circulation

¹ Columnist Rick Reilly, writing in *SPORTS ILLUSTRATED*:

In the red-cheeked glee afterward, Jake's mom, Liz, a single parent and a waitress at a coffee shop, ran up to the 295-pound Dewitt to thank him. But she was so emotional, no words would come.

Turns out that before the play Dewitt had called his defense over and said, "They're going to give the ball to number 45. Do not touch him! Open up a hole and let him score! Understand?"

It's not the kind of thing you expect to come out of a football coach's mouth, but then Derek Dewitt is not your typical coach. Originally from the Los Angeles area, he's the first black coach in the 57-year history of a conference made up of schools along the Ohio-Kentucky border. He'd already heard the *n* word at two road games this season, once through the windows of a locker room. Yet he was willing to give up his first shutout for a white kid he'd met only two hours earlier.

"I told Derek before the play, 'This is the young man we talked about on the phone,'" Frantz recalled. "'He's just going to get the ball and take a knee.' But Derek kept saying, 'No, I want him to score.' I couldn't talk him out of it!"

"I met Jake before the game, and I was so impressed," Dewitt said. "All my players knew him from track. So, when the time came, touching the ball just didn't seem good enough." (By the way, Dewitt and his team got their shutout the next week, 7-0 against Cincinnati Mariemont.)

too, harsh explicitly in its judgment of the coaches and the other players, and harsh—really harsh—implicitly in its judgment of Jake Porter. “Northwest didn’t win” the game, columnist Phil DiPirro felt obliged to remind us; “Jake didn’t either, and although he doesn’t know it, he was embarrassed.”² How so? “Because all those years, when Jake was treated as if he was a normal member of the football team, as if his Fragile X didn’t exist, were washed away in the waning seconds of an already-decided contest.”³ You see, Jake was treated *as if* he was a “normal” member of the team, but of course he was not, he had Fragile X; and once you stopped pretending that Jake’s Fragile X didn’t exist, you had to acknowledge that he really wasn’t normal, which of course embarrassed him, even though he didn’t know it. Or something like that.

But why, you might ask, couldn’t Jake be a “normal” member of the football team, with Fragile X? That is not an option, because, you see, Jake is—how shall we put it?—“special”: Jake “is special, a teenager who has overcome his mental retardation to become a three-sports varsity athlete and a beloved member of his community.”⁴ “Jake,” DiPirro advises, “has strived to be normal—to attend every practice like everyone else, to attend school each day like everyone else, for his entire high school career. By working so hard, Jake hoped that people would forget that he had such a horrible disease.”⁵

I won’t claim to know what Jake Porter hoped for from people, but I would bet that whatever it was—a sense of belonging, a connection, friendship, love—he felt plenty of it the night he scored his touchdown. And I would bet too that

[I]t became bigger than football. Since it happened, people in the two towns just seem to be treating one another better. Kids in the two schools walk around beaming.

“I have this bully in one of my [phys-ed] classes,” says Dewitt. “He’s a rough, out-for-himself type kid. The other day I saw him helping a couple of special-needs kids play basketball. I about fell over.”

Rick Reilly, *The Play of the Year*, SPORTS ILLUSTRATED, Vol. 97, No. 20 at 108 (Nov. 18, 2002).

“The importance of stories like this,” says Jeffrey Cohen, of the National Fragile X Foundation, “is that everyone has value. There are unique characteristics in the way that they learn, and creating a school and a community where everyone is involved is important.”

“I think this has done a lot for parents of kids with disabilities, and to me that means more than anything in the world,” said Northwest Coach Dave Frantz. “We’re all here for the kids, and if this helps people keep a positive outlook for those kids, then I will be thrilled.”

Northwest Superintendent of Schools Bob Ralstin concurred: “It gives our kids a sense of being thankful for what they have.”

And Liz Porter, Jake’s mother, said this about her two sons with Fragile X: “They’re really not any different than any other kids. They want to belong and they want to contribute.”

Dana Erickson, *Special Play Drawn for Special Player*, COLUMBUS DISPATCH, Oct. 24, 2002, at 1A.

²Phil DiPirro, *His TD Isn’t What’s Impressive*, US SPORTSPAGES.COM, Nov. 16, 2002, at <http://www.sportspages.com/blog/index.php?p=102&more=1>.

³ *Id.*

⁴ *Id.*

⁵ *Id.*

neither Jake Porter, nor the people who know and care about him, feel any need to forget about his “horrible disease.” Because what is really horrible is to insist that Jake’s “disease” *must be* horrible, so horrible that we must pretend that it does not exist, while at the same time yielding to its undeniable power to render its victims something other—something less—than “normal.”

DiPirro introduced the tragedy of Jake Porter this way: “Because he suffers from Fragile X Syndrome, Jake is mentally retarded.” And so shame on those who would challenge the natural order of things, and allow Jake Porter a touchdown; Jake Porter, after all, must “suffer from” Fragile X.

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Caleb’s parents had some decisions to make as first grade approached. The most important was the choice in school. Caleb was welcome to stay at his old school—a private Montessori school that included all the elementary grades—and that really was Caleb’s preference, but it now seemed to his parents a bad match. There were a few “special” schools in the area, but these were expensive, and hard to get into, and his parents really didn’t want to see him segregated, unless it was really necessary. They opted for the local public school, which had been their intent all along, before they had learned that their son was suffering from so many disorders. Caleb’s pediatrician approved of the decision. “Children are apples and oranges,” he had once observed, “and Caleb is a pineapple.” And in the public schools, Caleb would be in a more generous mix of fruits.

Caleb began his first day of school with minimal fuss and no apparent anxiety; the drop-off at school really could not have gone better. Not so the pick-up that afternoon.

Caleb was despondent.

“What’s wrong, honey?”

“Nothing.”

“Oh, come on; something’s wrong. I’ll bet you feel better if you talk about it.”

“Well, I got ‘called’”—“called” meaning, his parents deduced, “called upon, or ‘called out’ or scolded.

“What did you get ‘called’ for?”

“Which time?” Uh oh.

“How many times did you get ‘called’?”

“Twelve, probably, but one shouldn’t count, because it was for the same thing as another one.”

It was what his parents had feared. And worse than what they had feared, the new school had lots of rules—specific, concrete, and inflexible rules, enforced without exception, indeed, with a vengeance.

“You just need to learn the rules, honey. You’ll be fine.” But his parents really didn’t believe it.

The bubble burst the next day.

Caleb was crying as he left the school, quiet tears of genuine hurt that, in the course of the ride home, gradually gave way to chest-heaving sobs. His

teacher, it evolved, like all the other teachers at the school, rewards the well-behaved kids at the end of each school day with a little slip of paper, a note to parents or guardians that reads "Give me a hug. I had a great day at school today." The little notes are called "Happy Grams," and several kids in Caleb's class got one, but Caleb did not, even though he only had two "calls." And he was devastated. "But I try so hard," he cried, and there was no doubting his sincerity.

Caleb's parents knew that their son might never earn a "Happy Gram," but they chose not to share that insight with him. Instead, they encouraged him to keep trying, because trying was the most important thing. And whether or not he ever got a happy gram, it was important for him to know that his mommy and daddy were very proud of him, because he was a sweet, wonderful, loving boy, and mommy and daddy loved him very much.

And the thing is, all that was true, and his parents meant every word of it, which in some way crystallized things for them. And he knew it was true too, and he was still sad that he didn't get a happy gram, but it seemed now to matter much less.

"Did I earn a surprise for trying?"

"Sure, honey."

And at the end of the third day of school, he danced out of the building, waving a little yellow piece of paper. He had earned a "Happy Gram."

His parents suspected that his teacher felt sorry for him. He'd had three "calls" that day—one more than the day before—so it was hard to see how he had earned his "Happy Gram." But there would be no looking this gift horse in the mouth.

The first parent-teacher conference came at the end of the first semester. Caleb does daydream a bit, the teacher reported, but he's generally very engaged, and he's easy to refocus. He does sometimes have a hard time finishing his work, but a lot of kids do, and she can see improvement. "He's doing just fine," she said, and obviously meant it, which only stood to reason, seeing as how he had received forty-two straight "Happy Grams."

A few weeks later, Caleb received the "Citizen of the Month" award for his classroom behavior. His report card was somewhere in the good-to-excellent range, his math skills really blossomed, and his aptitude—and appetite—for reading seemed to improve exponentially. And above all, it could again be said, unequivocally, that he was a very happy child.

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There's no predicting the tenor or content of the next chapter of Caleb's life. But this much is certain: that his best chance for happiness rests with people who will resist the tendency to turn his differences into disorders, who will fight to ensure that his disorders are not disabling, and who will struggle against those forces that would cause him to "suffer from" his disabilities. There are many such people in the world; I pray that he always finds them.