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PRACTICE

Talking and Teaching About my Family: Personal Narratives, Disability, and Writing for Empathy

RACHEL KOOIKER

Growing up, I knew from an early age that my family was weird. Not *Malcolm in the Middle* weird or *Running with Scissors* weird. We were abnormal weird. Bulk-size boxes of adult diapers delivered to our home weekly weird. See, I was the “normal” child sandwiched between two siblings with a rare musculoskeletal syndrome, and my mother and grandmother operated a foster care home for adult women with developmental disabilities. My childhood was a bit unusual, to say the least, and that turned out to be one of my greatest assets as a classroom teacher. I didn’t always see my experiences that way, though. I’m ashamed to admit this, but for many years I struggled to accept my own family. I was embarrassed when people stared at us in public. I didn’t forgive my sister’s behavioral outbursts. I avoided having friends over for fear I would have to “explain” the random women walking around our yard or the strange babbling noises coming from inside the house.

It was not until I was an undergraduate English major that I began to understand the power of story—in my life and in the world. Years later, as a high school teacher working on a writing unit with my tenth graders, I realized that I *did* need to “explain” my family to people. My brother and sister have important stories and no way to tell them. I have important stories to tell because I grew up with a perspective on normal and abnormal that most people aren’t privy to. In this article, I’ll share how that realization led me to develop some specific and important pedagogical moves in my tenth-grade English classroom.

I hear the word *retard* every day. At work. On TV. I notice it a lot in the halls at school. Sadly, its usage isn’t limited to students. Adults seem to say it just as often as adolescents. Apparently this is one word that still isn’t taboo enough to cause a scandal. Sure, there are campaigns against the use of the word (End the R-Word, for one), and it is often recognized as a word that is hateful, brimming with the long history of prejudice and discrimination toward those with

disabilities. But this word is still common. While often privately dismayed at the flippant use of this word, what bothered me the most was that this usage is just a symptom of a much larger problem: it is just one of many daily injustices that people with disabilities are forced to deal with. Often, these injustices go unnoticed, except by those with disabilities, their friends, and their families.

Despite being bothered by the marginalization of people with disabilities in ways both large and small, I didn’t see what I could really do in my role as a teacher. My wake-up call came one evening when I read an angry journal entry written by a normally shy sophomore. She had composed a passionate piece expressing her personal outrage at hearing her peers use the word *retard*. In her journal entry, she explained her very close relationship with a cousin who has a severe cognitive disability. Coincidentally, I had just written a similar rant, angered by a co-worker tossing around the word *retarded* in conversation with me, completely oblivious to my horror at the word choice. That journal entry and my experience highlighted an important commonality; the people using the language were often unaware of how they were hurting those around them.

The timing of this student’s journal entry and the experience that drove my own personal writing spurred me to develop a writing workshop unit that would specifically address what my student and I both knew from our personal lives—namely, that people with disabilities are marginalized in ways that are largely invisible to the non-disabled. Since it is impossible and insulting to assume that one can “try on” and experience what it is like to have a disability, teachers can only encourage empathy without “walking in somebody else’s shoes.” For me, one small step toward solving this problem was to create a way for students to simply become aware of other people’s experiences through their stories. Specifically, I wanted my students to understand why they shouldn’t toss the word *retard* around, and I wanted them to know why that was important to me. I began this process by creating an

inquiry-based writing unit that my students and I would work through together using a workshop process.

The Writing Workshop

Out of necessity, the writing workshop was tied into a required piece of writing for tenth grade students, the personal narrative. The narrative was ideally suited for the inquiry and thinking that I wanted my students to engage in. Below, I describe each day of the workshop, with individual class periods lasting 70 minutes each.

Day 1: Before any writing took place, we engaged in a simple frontloading, pre-writing activity. First, I shared with students the poem that I had written in response to my experience with a co-worker (see below). Then, we had an in-depth class discussion in response to the question, “How do you deal with negative experiences?” We discussed how we respond internally, externally, emotionally, physically, and more. Then, in groups of three to four, I asked students to work together to create a one-page document (this could be a chat, graph, comic, list, etc.) that illustrated how they get past negative experiences. This moved us to think about how we process our reaction and work through the negative to get back to positivity.

Once students completed this work, we shared out. Student responses varied, but a common thread that we identified was that in each process of working through negativity, students had an outlet for the experience. The outlets identified by students included confiding in a parent or friend, venting in a journal, or engaging in physical activity. After this debriefing, I asked students a more challenging question: what would happen if the outlets you had were limited or non-existent? This was an intentionally difficult question, and I left students to think and write silently for the last five minutes of class. We did not share our thoughts or writing out loud; it was my intention to have students mull over this problem for a bit.

Day 2: Referring to our previous discussion, I introduced both the inquiry question that would drive our writing and the writing workshop. I told students that, for me, writing was an important way of moving beyond negative experiences. I explained that I noticed how many of them were emotionally impacted by my poem: they expressed outrage or sympathy; they asked questions about my family; they demanded to know who would use such a word. It seemed like my sharing of a personal poem allowed them to tap into the feelings that negative experience caused for me, even

though it didn’t happen to them. I then introduced the goal: we would be working on a personal narrative assignment, and it would be driven by our questions and answers related to the following questions: What stories really need to be told? I used this as our inquiry question because it addressed directly what I wanted to think and write about. The question was significant and not isn’t easily answered, and it allowed students to think and write in many directions, so that they had choice in their writing topics.

My students were familiar with the writing workshop methods that were used, and so little direct teaching was required to establish workshop procedures. My writing workshop format was shaped by Penny Kittle’s methods (as described in *Write Beside Them*), and I started the writing process by working through my own rough draft right in front of students.

Day 3: I wrote a rough draft that told the story of an experience that my sister had on the school bus, here is an excerpt:

Most of the stories about my childhood are funny, if only in the way that the absurd becomes laughable when there is no other way to treat it. But many of the stories I have aren’t funny, not in any sense. For example, the many fire drills my older sister endured, while I looked on, passive.

My sister and I rode the bus to school for 35 long, dreadful minutes, and sometimes these bus rides were extended by perfunctory fire drills. The biggest kids, usually a couple of meaty sixth grade boys, routinely volunteered to jump down first so that they could help the smaller ones down when it was their turn. One by one, students big and small were safely hoisted by their armpits to the ground. I was already waiting in the parking lot when I saw my sister’s chubby body fill the emergency exit. “One, two . . .” the sixth graders counted, and my sister spread her arms, waiting to find helping hands.

But on “three” there were no helping hands. There was air. There were the flailing arms of my sister as she fell two feet, face-first, to the pavement. There was me, a third-grader, looking on. Nobody else knew that Amber’s blood didn’t clot. Nobody else knew that any bleeding, internal or external, major or minor, could be fatal for her. But I stood silent.

I was too afraid to do anything. At nine years old, I was learning from my peers that people like Amber didn't deserve any better.

Luckily, Amber suffered only minor scrapes and bruises; physically, anyway. The bus driver wrote up an incident report, I'm sure, but the whole ordeal was discussed as an unfortunate "accident." I knew better. Everyone knew better.

I shared this narrative with my students using Google Drive, and I invited them to comment on what they read. When my students commented on my draft, they didn't only comment on the writing, they also responded emotionally and empathetically to my sister. One boy lambasted my lack of response with the comment, "She could have died." Many students wrote about how sorry they felt for Amber. Others expressed disbelief: how could students have actually done that? I think they were all a little bit like the nine-year-old me, unwilling to accept that cruelty kids can be cruel, too.

Days 4-5: After reading and commenting on my rough draft, students set out to write their own narratives. I made revisions on mine and thought about what to share with them next. In the second draft of my narrative, I added the following piece:

When my sister was a tenth grader, a popular boy in her high school class exposed himself to her in the hallway. This pervert didn't receive so much as a detention. If I were a teacher at that school, I'd want him in shackles and chains, paraded around the school for all to see his punishment. For weeks, my mom tried to get the school to punish this cretin in some way. I'm not sure what happened; maybe none of the school employees could verify the story. Maybe some people could, but didn't step up to help out. Maybe the old saying "boys will be boys" was spoken at some point. All I think that I know for sure is that if an incident like this had happened to another kid, a kid the teachers knew and loved, there would have been a bit more done about it. But there my sister was, a victim not even adults would stand up for. At the time, I was a seventh grader who was pretty oblivious to Amber's struggles. There is no way I could have imagined what that humiliating experience was like for her or my mom.

My students continued to comment with fervor on my draft. I had to ask students to stop commenting so that they

could work on their own writing. The students who were shocked by the bus incident couldn't believe this story. Their words and comments continued to reflect sincere compassion and empathy. Throughout this drafting, sharing, and revising process, students were also sharing their own work with me and 1-2 classmates, using the same peer revision process I modeled. We were also calling attention to and working on important writing skills; I was showing them how I reorganized my piece for this effect or that, and I was modeling word choice revision. Most importantly, we discussed throughout the commenting process how my story (which was really my sister's story) was evoking empathy and compassion. We were beginning to answer our big question—*What stories should be told?*—by looking at the effect of our personal stories had on our classmates.

Day 6: To help answer our main inquiry, I added more to my own narrative. The next section of my piece addressed how the experiences my sister had growing up shaped the ideals and values that I now hold and wanted to share:

I don't know what made me start thinking about my sister's school experiences so much. Some people might have just shook their heads in disgust and walked away from the memories. I couldn't, can't, and now won't shake them off. Yet, I didn't have a sudden epiphany. There was no revelation from a burning bush telling me to go forth and teach. But eventually I centered on the idea that I learned to be tolerant and was given different ways of looking at the world through reading. I also wrote. I wrote to understand, I wrote to tell others about the world of disability that I grew up in.

And that is what is powerful about teaching. It doesn't always take walking in someone else's shoes to be able to care about their lives; sometimes it is only listening to the stories that they tell. So this is what I think about when I think about teaching. I think of the silent torture of those kids who are placed in the position of being a victim, but aren't allowed to have a say. I think of the untold or unheard stories like my sister's. In her case, disability stops people from looking beyond her grubby appearance and listening to her stories.

Sometimes it is race, poverty, or appearances, but the fact remains that there are a lot of things that stop us from listening to and caring about the people we

walk this earth with. There are things that hold people back from telling their stories, too. Some people can't write or speak for themselves.

"It is really cool to see why you wanted to be a teacher," was the first comment I received on that section of writing. In this round of peer revision, I asked students whether or not the conclusion was definite enough. I wasn't attempting to lead them to the correct answer—I was actually worried about the conclusion in my narrative. I still felt as though I hadn't really said what I felt needed to be said about what teachers and schools can do for or to people with disabilities. My students agreed. They told that they wanted a stronger conclusion, one with more emotion. This is what my students led me to write and understand:

For me, the choice to become a writer and an English teacher was driven by the realization that if I wanted the future to be a safer, more aware place for people of all perspectives, then I needed to be a teacher. Now, as a writer I have to tell stories about the worlds I live in. Now, as an English teacher, I need to show my students that listening to the stories of others creates one world linked through the power of our shared experiences.

Days 7-9: While that excerpt is the end of my personal narrative, it isn't the end of my writing experience with my students. We needed to polish and share our writing. We used two days to discuss grammatical revisions to our work, and the last day of our unit was a writing celebration. I had seen many version of my students' narratives, and I was excited to hold a read-around of all our work on the day the narratives were due. I explained how we would share our writing: one person at a time, sitting in a comfortable circle with hot cocoa, and each writer could share as much or as little as he/she pleased. Students were apprehensive about reading in class, but quickly became engaged as they listened to the words of their classmates. The narratives were deep, thoughtful, and often profound.

One thing that I couldn't help but notice was that many students had reflected on their experiences with disability. Most memorable was Megan's essay, which she proudly agreed to let me share excerpts of here. She wrote about her sister Mary, who has a disability that, along with other things, affects her speech. She and her family have taken to calling Mary's way of speaking "Marrish." Megan reflected about what this has taught her and others here:

Mary is my little angel sister. From the outside she looks and acts like a "normal" kid, but on the inside she is a little mystery that even my family can't solve

sometimes. Mary calls me 'E' because she can't pronounce Megan. She calls George 'Orssshaa!' Mary has probably heard my mom and dad scream my brother's name so many times she started calling him that. I have grown up just knowing the 'little sayings,' as we call them, and figuring out at an early age that some people have challenges makes my life seem extremely easy.

Megan's narrative also included an episode where another girl grew impatient with Mary, and wouldn't play with her because she grew frustrated trying to understand her. Megan left her audience with this plea, which I pass on to you:

Everyone should learn to speak Marrish. If we could all see the world through the eyes of a child with special needs, we would be so much better off. That is how Mary has made me a better person and shapes my life.

Another student, Andrea, shares in her narrative her experiences growing up with a mother who struggled with alcoholism and a father who had an untreated mental illness:

Most eight-year-old children don't know much about the real world, and most eight-year-old children haven't a worry in the world. Most have their own possessions and have a loving family who they live with for their countless years before leaving the nest. I, however, was not a normal eight-year old-child. When I was eight years old, I wasn't frolicking around a playground or at a bowling birthday party; I was being taken away from my biological family. My mother was a green thumbed gardener, fantastic cook, avid reader, and an alcoholic. She struggled with drinking problems throughout most of her life and developed a brain tumor at the age of about thirty five. She was in no way fit to take care of two rambunctious children. As for my father, his struggle wasn't a physical addiction, but a mental illness. Anger seized him as a lion would a lamb, and he had fits of rage. Often times without warning, he would leave our family alone while he went away for weeks at a time.

Day 10: The read-around could not have gone better. Students were engaged, and they were proud of and invested in their stories. Still, we needed to revisit our original inquiry question: What stories really need to be told? Students reflected on this by writing in their journals for approximately fifteen minutes. I prompted them to consider the stories that their classmates had told, and to think about why it was

important that those stories were told. Their writing revealed that many had gained new knowledge about one another, and that the process of writing and listening to stories had opened up new ways of looking at each other, as demonstrated in this student reflection:

I thought it was a very powerful, profound, and beautiful story, and it brought tears to my eyes. Most of us don't share our backgrounds with each other, and Megan's story showed that you never know when something you say or do might mean something more, which can be good and bad.

The overall experience with this writing workshop has affirmed the power of storytelling for me. I believe that simply sharing my stories with my students may be the most powerful tool I have for changing minds and our world. Together, voices like Megan's and mine can combine in powerful ways. I am no longer the wary nine-year-old schoolgirl who doesn't know how to protect her sister from school bullies. I am a teacher who can both tell stories and help students tell stories that can help change us all.

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Retard

Talking about her fifth hour class
She slung one word through the air
Carelessly
Without being the slightest bit aware
Of my disdain
For the term

She did something that revealed
A portion of her character
And mine

I kept my jaw sealed

If that had been a student of mine
I might have asked
"Could you choose another word?"

Out of the vast array of words
in the English language
the many nouns and adjectives at our disposal
she arrives at that one

without knowing, of course
what it is like to have a disability
without knowing, of course,
what it is like to hear the word retard
thrown around here and there
synonymous with gay, stupid, bad
synonymous with you-
if you happen to be "slow"
if you happen to be disabled
if you happen to be my sister
if you happen to be my brother

but unlike the n-word – unlike
other derogatory labels
there hasn't been enough
fuss and commotion
to carry through a linguistic revolution
but rather those with ignorant minds pollute
our word population with an n-word dilution
come on-
could you choose another word?

—Rachel Kooiker