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**Upward Bound: Collected Stories** 

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## UNIVERSITY OF CALIFORNIA, LOS ANGELES

# UPWARD BOUND COLLECTED STORIES

#### A THESIS SUBMITTED TO

#### THE DEPARTMENT OF ENGLISH

#### IN PARTIAL FULFILLMENT OF THE DEGREE OF BACHELOR OF ARTS

BY

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#### ABSTRACT

#### **UPWARD BOUND: COLLECTED STORIES**

#### BY WOODY BROWN

The CDC currently reports that 1 in 44 children have been identified on the autism spectrum. Most people think of quirky kids and savant skills when they think about autism, if they think of it at all. Some cruel professional came up with the terms high- and low-functioning to define the two ends of the autism spectrum. The autistics seen on TV or social media are on the high-functioning end: socially awkward, but verbal and able to exist in society. What about the autistics on the other end of the spectrum? The nonspeakers, the behavioral challenges, the kids who are segregated out of the neurotypical school population, never to be seen again? What happens to those profoundly autistic kids when they age out of the school system and become adults? This matters to me because I am profoundly autistic and nonspeaking. I saw firsthand what the system had in mind for my future. It was an adult day care facility where I would be babysat so that society would be safe from me. I defied that outcome by learning to point at a letterboard to communicate. Spelling allowed me to defy expectations and has given me the means to tell the stories from inside that center. My stories are the voices of Upward Bound, a fictional day care center for autistic adults. Each story is from a different perspective: clients, staff, director. This collection is dedicated to my autistic peers who have not yet been given the tools to communicate.

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#### The Eloper

I've spent plenty of time with Jorge. I probably understand his predicament better than the people whose job it is to handle him. Jorge and I are both inmates at an insane asylum that passes itself off as a day program for autistic young adults. We have been in and out of each other's lives since special ed preschool. We graduated from different schools -- well, I graduated, he got a certificate of completion. But there is only one place in this city for people like us to go after high school, so here we are. Reunited.

Jorge and I have shared space off and on for nearly 20 years, but we have never had anything that resembles a conversation. That probably seems incredible, but it's standard operating procedure for nonspeakers. Jorge has an admirable level of acceptance about his situation. He doesn't seem consumed by the frustration, anxiety and anger that tortures many people who lack speech. Some of us are like tightly wound tops. With a flick of a wrist, we can spin and skitter out of control. Not Jorge. He falls into the category of gentle giant. The first thing you notice about Jorge is his immense size. He is tall, but he is almost as big around as he is up and down. He usually slumps and hangs his head, as if the act of being big ol' Jorge is a weighty burden. He is the least aggressive inmate – I should say client – in this sad, boring place. He's too big to move with any conscious belligerence, and he's too gentle to get riled in the first place. Jorge presents only one behavioral challenge at Upward Bound, which is probably the most cynical name they could have given this dead-end waystation. Jorge is what they call an eloper. If you look away for an instant, Jorge is gone. He moves like a specter when no eyeballs are trained on him. This isn't a problem most of the time, the adult babysitters keep the doors

locked in this place. But when we go on our weekly field trips to Target, a staffer is assigned specifically to Jorge. Thankfully, I don't require this level of supervision.

People can be elitist when it comes to speech. If you can't communicate, it must mean that you are mentally retarded. In the special ed room, Math consisted of learning how to make change and English meant picture books. Unlike Jorge, I had a ticket out. My parents refused to accept that I was an idiot. They saw this Indian lady on 60 Minutes who had taught her nonspeaking son to type and they tracked her down. I was three when I met Soma. She showed me how to point and make choices of words and letters. By the time I started school, I could spell and do simple math better than my neurotypical peers. The catch was that I needed an aide beside me to hold up the little laminated board with a QWERTY alphabet and basic punctuation marks on it. The aide needed to be trained to help me stay on task.

Autism on my end of the spectrum is like ADHD times a thousand. It's nearly impossible for me to untangle the many channels in my brain so that I can stay on a single station. It's like sitting in front of a bank of monitors that are all showing videos of different events, and all are playing at top volume. The aide uses prompts, repeating the letter or word I've just pointed to, to keep me on track so that I can complete a thought. My brain can easily switch to another channel and the communication drifts away unfinished. The aide shakes the letter board when I get derailed, to regain my attention. The sustaining of my attention is a dance of subtle cues and prompts. It's not a dance you learn at the first try. Training can take a while, but it's crucial. It's also important that the aide have a core of calm. I pick up on the energy. My focus is obliterated if the person helping me is stressed or lacks confidence. Good soul + good training = good aide. A tall order for a low-paying gig.

The public school had no idea what to do with me. My mom tried to show them, offered to train an aide, just as she had been trained by Soma. School administrators said no. I kept going to school, bored and chagrined in special ed. Mom had to work, but she worked from home as a technical writer. If you have a kid like me, you have to be flexible. Mom spent several hours after school giving me little lessons in math, science, and history. She made the school give her the textbooks that the typical kids worked from. She read to me every day, from children's classics and poetry. She kept me at grade level. I must confess that my behavior during this period was challenging to say the least. I was not submitting quietly to instruction. The special ed teacher and the school psychologist might presume that I didn't want to learn. My mom forged ahead anyway. I don't know which came first: my desire to learn or her passion for me to get a proper education. At any rate, I was finally allowed to sit in the corner of the remedial class where I worked with my aide one on one. It felt like my life finally began the day the teacher invited me to join the remedial learners in a group lesson. Thanks to my mom's sessions at home, I was already ahead of the other students. I didn't mind. It gave me the bandwidth I needed to work on controlling my autistic behaviors in class.

By the time I hit high school, I was on diploma track. This constituted a minor miracle. Most of the severely autistic kids I started out with had been quietly shunted off to special schools where they couldn't bother anyone but each other. Jorge was bussed to some place an hour away. None of us were expected to meet graduation requirements. My pointing and typing gave me entrée to a different outcome. I often wondered why the school district didn't try to replicate what I was doing with the others, like Jorge. I guess it was just too perplexing, or too much work. Or they had no warrior mom to force them into educating the losers they assumed to be ineducable.

I had another advantage. I had an aide who stuck with me through middle and high school. School aides usually come and go. Sal was a big, friendly teddy bear who excelled at being my protector. The social anxiety of being a nonspeaking oddball at a big public high school was intense. Sal was like a comfort item who never got annoyed with me and always had my back. He may never have attained greatness as an aide with the letterboard. He didn't have the fluency of the dance that Soma and my mom did, but he kept me calm and in the room. His face was so full of joy the night I crossed the high school stage and accepted my diploma. The accomplishment was his as much as mine. You should have seen my mom that night. She was weeping so hard she could barely speak.

But what next? The supports fall off after high school, like training wheels that I still needed to stay upright and moving forward. My parents refused to give into the inevitability of Upward Bound. But college seemed like a nonstarter. How could I sit through a long lecture without making my weird noises? How could I even get into college with my spotty academic record? They don't let you have a communication partner to take the SATs. My mom had a realization. All you need to go to community college is a high school diploma, and I had one of those. I applied online and never had to mention my disability. Mom tried to hire and train an aide to go with me, but the first two quit. It was also incredibly expensive. There is public funding for caregivers who babysit, but not for academic support. Mom decided it would be easier to do it herself. She and my dad agreed that she would quit her job and she would be my aide at community college. It was an experiment.

I started with just one academic class. English 1A. Mom and I walked into the rundown old classroom. I made a beeline for the seat in the back row, farthest corner. I chose that so I would be less inclined to leave for an unscheduled break. The professor talked about herself and

the books we'd be reading. She had everyone make a brief introduction. Mom held the letterboard so that I could say it in my own words, which she read out loud. I thought we'd come across like a freak show, but no one batted an eye. Many students in the class had obstacles they had faced to be there. I wasn't the only outlier, it was a room full of outliers. The ninety-minute class flew by. It never occurred to me to take a break. Mom and I drove to campus for class every day, but I didn't hang out or study there. It was too chaotic for me. At home we worked on a strict schedule of reading and writing. Half hour of work, half hour of break, starting at 8 am and ending at 5 pm. Dad, who worked from home too, would stick his head in the door throughout the day, just to get some attention. Mom would pretend to be aggravated by the disruption, but being annoying was Dad's schtick. I enjoyed their banter. After 5, my brain needed the calming effects of my video screens, dinner and an early bedtime routine, which Dad oversaw.

The first real test was the mid-term paper. I was never asked to write one in high school. As much as I wish I could just type my thoughts independently, that's not how it works for most nonspeaking spellers. Our brains have trouble getting all the motor planning lined up to perform the complex actions involved in typed communication. Most people don't consider how many parts of the brain are activated when they speak or type. If your electronic impulses resist firing in the right order, like mine and probably Jorge's do, the message gets lost somewhere between the thought and the finger hitting the keyboard. I needed Sal in high school for many reasons, but he lacked the structural organization to assist me in longer assignments like a paper. Mom figured things out as she went. First she elicited from me a topic. I typed, "Assuming intelligence." That took one half-hour session. The next day she had me type out a thesis, then supporting ideas that became an outline. In thirty-minute increments, daily over several weeks, I

wrote a paper. I fashioned every idea and wrote every word, although I could not have executed any of it without Mom holding the board and keeping my brain on track.

"Okay, you've said you want to write about assuming intelligence. What are you thinking of for a thesis?" she said.

My fingers hopped across my letterboard. She repeated the words as I typed them, then she repeated them again as she typed them into the computer when I finished a phrase or sentence. The repetition maintained my focus and momentum.

"Many. autistic. students. do. not. at. first. glance. appear. to. be. capable. of. sophisticated. thought.," she answered back my words twice as my fingers danced across the little board. Yes, I could have typed directly onto the computer keyboard myself. But my shaky fine motor skills make my fingers detour to neighboring letters. I would spend more time fixing typos than writing. The simple, low-tech, laminated letter board, that we made from a computer printout, is forgiving if my finger goes a little off the mark.

That first paper got an A. What the hell. I kept challenging myself. I went from taking one class per semester to two, then three. I kept getting A's. I took all the general ed classes I needed to get my AA and transfer to university. I could see a path in front of me.

Jorge, on the other hand, was taken out of his public school by the district when he was in the fifth grade. They sent him to a non-public school that catered specifically to autistic students. Everyone felt good about sending Jorge and the others to a specialized school. My mom toured it around that time. She was always on the lookout for a place where academics were a priority, where she didn't have to work so hard to convince people that I could learn the regular stuff. She came back annoyed. It was no better than the dummy special ed class at my current school. Some of her autism mom friends liked it just fine and sent their kids there. The problem was that a

school like that didn't prepare autistic kids for anything except a lifetime at Upward Bound or its equivalent. The more regulated among us might look forward to a career as a box boy or a busboy, but the nonspeakers can't even do those menial jobs. An education might expose areas of strength that could lead to a more productive life, and a richer inner life. For Jorge and most of the others I grew up with, their dependence would be lifelong.

The bottom line is being able to communicate. I wonder if Jorge could have learned in school if an iPad and a trained aide had been available to him. You can see how helpful some alternative communication would have been. Hey Jorge! Why do you keep running off? What can we do to keep you in your prescribed location? If Jorge could point and type like me, we could get to the bottom of this dangerous mystery. Unfortunately for him, there are very few aides trained in alternative communication. There are none at Upward Bound. Here, without a real communication partner, I am as mute as Jorge. Even if I knew with certainty why Jorge wanders away and what our minders could do to keep him safe, I would have no means to tell them.

Upward Bound is located in a shabby, one-story building that used to be a nursing home. It looks like a sixties-era ranch house that's been stretched out at the sides and painted a forbidding shade of brown. If Dickens had lived in mid-century L.A., he would have put Miss Havisham in there. The inmates have to sign in at the front desk when they arrive in the morning, or someone does it for them. I am capable of signing my name, but it takes me forever and looks like a kindergartner's scrawl, so I let my mom do it. There are various rooms, patios and a dinky, kidney-shaped pool surrounded by cracked concrete in the back. Most of the action (a term that applies very loosely) takes place in a large rec room in the center. Picture a nursing home rec room that hasn't been updated since the Carter administration. Old school linoleum, accordion

dividers, metal folding chairs, cheesy decorations hung for whatever holiday just passed. They feed us breakfast, which usually consists of generic sugary cereal in a Styrofoam bowl. The schedule for the day is scribbled on a big whiteboard in hourly increments. It is one infantilizing activity after another. An hour of gluing macaroni to popsicle sticks to make a picture frame. An hour of a "cooking" activity during which we make Chex Mix, combining processed salty and sweet bits in one big bowl, which we eat for snack. There might be a walk across the street to the park, where we big-ass adults sit on swings or meander about. Staffers casually surround the playground to keep elopers like Jorge contained. Lunch (even less nutritious than breakfast or snack), games like Cootie or Connect 4, maybe a swim if it's warm. The time in the pool doesn't suck, but still, one day feels like forever.

God knows I feel like dashing out screaming from this place a million times a day. But I have more self-control than that, and am able to play the model inmate. Still, I don't get much intellectual stimulation here, so I've put some effort into forming theories about Jorge's dilemma. The most likely one is that Jorge isn't running away from anything. Jorge doesn't mean to escape. He is going *to* something. There is something somewhere else that he wants to see or do. He can't express his need, so he just goes. The staffers have never even noticed that every time Jorge has eluded them in Target, they find him in the toy section looking at Mr. Potatohead. I have no idea what the spud's appeal is to Jorge. The compulsion is so strong that you can see Jorge's brain visibly thrumming as soon as our clown car pulls into the Target parking lot. If I could, I would tell the staffers to make the toy section our first stop and give poor Jorge his Potatohead time before his head explodes and he runs away.

Jorge, the other inmates and I were just marking time at Upward Bound under the notvery-watchful eyes of the young, underpaid staffers. I was older than most of them. Many were from the nearby community college (two were my former classmates, talk about irony). Some were full time, if they couldn't find a better job. They were a mixed bag. Some tried to engage, some were bored and snuck their phones out of their pockets when the supervisor was out of the room. If I could speak, I might have snitched on them. Sometimes there would be a staffer who took a shine to you and would hang out with you in particular. I attracted a few fans due to my intriguing, tragic circumstances, but turnover is high in crappy jobs like this, and none of my staffer pals lasted very long.

Darla is in law school now. She flirted with me, in the way a smart, well-intended girl tries to make the autistic guy feel like he could actually have a girlfriend some day. It wasn't real, but attention from a pretty girl made the time go by faster. She knew I had gone to community college. She had gone there too and said she remembered seeing me on campus. I realize that I was memorable for looking weird and having my mother at my elbow. Still, I was flattered. I'm pretty sure she thought I was there as part of some autism program. I wanted so badly to tell her that I was a straight-up student with straight A's. I bet she would have appreciated that I was an English major and that I dreamed of supporting myself as a novelist. I would have told her that I wouldn't have minded working at a menial job, but my body is so disorganized that I would wander around aimlessly without someone to steer me in the right direction. I would have told her all that if my letter board weren't lying fallow at home, as useless as my AA diploma. But all I could do was try to keep my behaviors under control when she was near.

Even vocational programs for autistic adults refused to take me on. Becoming a novelist was a long shot, but the alternative was day care. Surely something would happen to prevent that.

Something did happen. My dad, the most funny, loving person in the world, had a heart attack and died right after my community college graduation. It was so shocking that my mom and I were completely paralyzed for a couple of months. My little family was a three-legged stool. Missing a leg meant that we tottered and fell.

Mom and I met with the lawyer and accountant. There was life insurance and whatnot, but it wasn't going to be enough to take care of us forever. I would have loved to have gotten an actual job, but the door to the working world was bolted from the inside. Mom realized that she would have to go back to work. She couldn't get her old job back, but she got hired as an administrative assistant at a big hospital.

I'm not able to go unsupervised, despite my age and intellect. There are several reasons for this. For one thing, I can't call 911. If there were an emergency, if I accidentally set a kitchen fire, I would be unable to initiate a phone call. I can perform routine tasks that I've done a million times, but the novel event paralyzes my body. Here's a far more likely scenario. I have this tendency to vocalize along with my videos. The more stressed I am, the more likely I am to play stressy clips, like the incinerator scene from *Toy Story* 3. My voice can get alarmingly high and shrieky. If it gets to be too much, Mom will come tell me to tone it down. If I were alone, there would be no checks on my behavior. Suppose a neighbor called the police because they heard screaming, as if someone were descending inexorably toward a fiery hellhole. Disturbing, no argument. Cop comes to the door. I would not be able to identify myself or answer the officer's questions. I would end up in a psych ward. No joke. It has happened to other nonspeakers we know. There are plenty of stories of people like me being mishandled in interactions with authorities.

So we were forced to stick me at Upward Bound for my safety. We insisted to each other that it was temporary, that Mom would find a better place for me, where nonspeakers were respected and their communication was facilitated.

No utopia has presented itself. And adult day care is adult day care.

Darla made my first few weeks at Upward Bound more bearable. Unfortunately, she left for law school. I didn't blame her. Staffers here have to put up with some tough stuff. Darla's duties included changing diapers, cleaning poop and vomit, and dealing with meltdowns. Some of which may have been mine. It's one thing when the population is tiny kids, but when the soiled underpants belong to a severely autistic adult, many staffers decide that working at McDonalds would be less of a hassle. I can only imagine that working here would make law school look like fun. I almost got it together to hug Darla on her last day, but my body chose instead to flee the scene. I'm hoping that Darla realized how much I appreciated her attention. I hope she remembers me a little.

Jorge was luckier than me. He developed a bond with a guy named Carlos, who was a little older than the average zookeeper. Carlos was as thin and wiry as Jorge was large and floppy. They gave off a copacetic vibe though. Both were undemanding and were never cranky. Carlos was surprisingly competent in a quiet way that could go unnoticed. Jorge was quietly complacent and also often overlooked. They would naturally seek each other out in the group, and sit together like a couple of satisfied buddhas. If there was a small group activity, like playing Hungry Hungry Hippos or making puppets out of paper bags, Carlos always kept Jorge in his section. Unlike Darla who was on her way somewhere else, Carlos seemed like a lifer. He looked as if he actually enjoyed the work. He didn't have his heart set on some other more respectable, better paying career. He liked it just fine at Upward Bound. Carlos told me and

Jorge one day that he had saved up enough to buy a kayak. He had a group of friends who were into outdoorsy things, and he enjoyed being out on the water. I entertained myself with fantasies of being one of Carlos' outdoorsy friends. I don't know if Jorge did that too, but the gentle bear loved to hear Carlos tell stories about his weekend of hiking or kayaking.

I admit that I had unflattering feelings of jealousy when I observed moments of connection between Carlos and Jorge. It wasn't just that they naturally drifted towards one another during activities. Or that Carlos had eyes in the back of his head, looking out in case one of the bullying guys snarked at Jorge. Not all of us here are nonspeaking, and some use their powers of speech for evil. There was one day when a mean jerk was mocking Jorge mercilessly. The jerk probably gets crap from typical guys all the time, but here he's an alpha dog and he takes out his frustration on a guy who can't answer back. Carlos came out of nowhere and moved in on the bully. He's not allowed to manhandle the clients, but he has this zen way of getting in between oppressor and oppressed and de-escalating a tense situation. He drew the bully away and quietly corrected him, allowing him to save face, while Jorge slumped off. That wasn't what made me feel envious. It was a half-hour later. I saw Jorge sitting with his head down, and Carlos was sitting next to him, not saying anything, not even looking directly at him. He was just there. It was a static tableau that communicated the entire scope of their relationship. Jorge takes comfort in Carlos, and Carlos comprehends what Jorge needs without language.

Imagine how ridiculous it was for me to be envious of Jorge, who couldn't even type, much less sit and learn in a proper classroom. My AA degree looked small and useless in the light that emanated from this contented pair of souls. It made me think of me and my mother. We could also be found at the end of a long day, sitting in silence with our heads hung low. Only there was no peaceful contentment, at least not yet. Maybe never. It wasn't that Mom hated her

new job, although she probably did. And it wasn't about the downsizing and economizing we had to do now. It was the absence of the happy disruptions that my dad brought to our days, which were now flat and way too consistent. Autistic persons love routine, but I always appreciated how Dad busted me out of my OCD patterns with his nudgy protestations of love. I'm not sure what my mom's version of this feeling was, but she looked as if she had been bullied by life itself, and I wasn't up to the caretaking role that Carlos played with Jorge.

I was feeling sorry for myself. I had good reasons, no question. Here was this big, galumphy guy, who I had every right to feel superior to, and I envied him. The bottom of the barrel wasn't low enough for me. I was going to have to invent a whole new metaphor to describe how worthless my life had become. When I was in high school, and especially at community college, I had a mission. I was a speech-free guy with autism up the wazoo, but I could type and prove that I was as smart as anyone. I was special, in a good way. Now, more than I had felt in years, I was special ed. I had no way of letting people know who I was, and my exterior presentation led people to make demeaning assumptions about me. My intelligence was like the rock pushed up the hill by Sisyphus. I could never get it to the top.

I was sitting in the rec room, waiting to be told what to do next. There were probably a dozen of us inmates in this familiar holding pattern. Staffers were there, but they were huddled in a group, talking with great animation about an episode of *Love Island*. Mom wouldn't watch that show so I haven't seen it either. Sounds contentious but also sexy. If Carlos were there, he'd tell them to get back to work, but he'd say it in a cool way that wouldn't make anyone resentful. The staffers obviously felt no urgency to set up the next activity. You could tell that it didn't even occur to them that we might mind being left to rot like diseased corpses. As if time means

nothing to people who have nothing but time. I think it's the opposite. Our time is wasted so profligately that we cherish time for what it might be, not for its emptiness.

Such were the thoughts that occupied me in lieu of an occupation. While I waited for the staffers to remember their jobs, I saw Jorge out of the corner of my eye. As I said he is utter stealth itself when in escape mode. He slipped out of the room via a lesser-used back door that leads to the pool area and the parking lot. I doubted seriously whether Jorge was plotting an escape attempt or to take an unauthorized swim. But someone ought to know that he'd left the building. I went through my available scripts to find a Thomas or *Toy Story* phrase that I could utter that would function in this situation. For reasons I can't explain, I am not able to summon a timely, unique message that I can say with my mouth. I can, however, repeat a phrase from an often-viewed video. They call this "echolalia" for what it's worth. In this particular moment, the best I could come up with was:

"Thomas has left the station."

I am the echolalic guy who cried wolf too many times, so naturally, no one paid the slightest attention to my important message. My mom is the only one capable of translating my echolalic scripts into functional communication. Everyone else assumes my phrases are nonsense to be ignored. Mom's not here, so my nonsense was ignored. The staffers didn't even look in my direction, and the other inmates have been trained to be useless. I sat for a moment, but then I lumbered to my feet. It took heavy concentration and motor planning to propel my awkward body in the direction Jorge had gone. My idea was to double the chance that someone would notice a client was missing. I had no personal reason to flee. My top priorities are familiarity and routine, and this action provided neither. But I also didn't want anything to happen to Jorge. I came through the door into a corner of the parking lot. The pool was to my right, but it was gated

and locked. I couldn't see Jorge anywhere. The car entrance was open, so I walked in that direction to see if he had gone off the property. Then I glanced over to the little grassy area tucked away on the other side of the parking lot. There were a couple of play apparati there, and it was shady. I walked over there. I could see Jorge's big feet sticking out of the terra cotta tunnel. I knew that spot. It's cool and quiet in there. I had no need to disturb him now that I had found him. I would just wait for someone to come along. There was a bench next to the basketball hoop. I sat down. I counted cars that passed. There weren't many.

It seemed like forever, but finally and abruptly, the main back door blew open and Carlos and Andy rushed out. Now there was a little urgency. Andy ran towards the entrance to the street. Carlos slowly walked over to me. Like, in case I was scared or skittish, he didn't want to startle me. I was fine, I was just glad it was Carlos. I tried to point to where Jorge was, but my body wouldn't cooperate. I also tried to summon a non-echolalic word, like "tunnel" or "Jorge," but my mouth wouldn't work either. Finally I just got up and walked over to where Jorge lay. Carlos said very gently, "Hey buddy, been looking all over for you." Jorge was happy to see Carlos. He got up out of the tunnel with a smile on his face.

"C'mon guys. It's snack time."

The three of us walked back to the rec room, where the tension level was a lot higher than when we left. Mike was there, trying to question the clients about where we were, but that didn't seem to be going well. A staffer saw us and cried out. "There they are!" People rushed toward us, but Mike stepped in and had Carlos take us to Mike's office. Mike sat at his desk with a serious look on his face.

"I hope you realize what a dangerous, thoughtless thing you did today. At Upward Bound our priority is the safety of our clients. I can't do my job if you leave without permission."

Mike was like a school principal chewing out a couple of truants. I stopped listening. The people who deserved a lecture were the staffers who weren't doing their jobs. I'm sure they covered their asses, while I was helpless to explain what happened or defend myself.

"I am going to have to file an incident report on both of you. I'll send a copy of it home."

An incident report from an adult day care center doesn't sound like a big deal, but it is.

An incident report leads to more restrictions, and too many of them means that they send you to a different place. There are worse places than this. If this facility is a rundown bore, the place for adults deemed too aggressive for rundown boredom is closer to autism jail. Wouldn't that be ironic, to go from college to lockdown because I helped them find Jorge. Carlos, bless him, seemed to have a clearer view of the event.

"Mike, I don't think these guys were intentionally breaking the rules. I think Jorge needed a time out, and Walter was looking out for him. Walter showed me where Jorge was."

That took away a little of Mike's bluster. "Well, Jorge should have let someone know he needed a time out." That ridiculous statement hovered in the air like a stinky fart. The more you thought about it, the worse it got. If Jorge could let anyone know anything about him, he probably wouldn't need to be here. Ahem, me too. But I'm coming off okay in Carlos' telling, so maybe I'll be spared.

"Well, I guess that's possible," Mike said. "But still, we have to be consistent. They broke the rules big time, and I'm obligated to file incident reports. I could be the one in trouble if headquarters found out." Mike filled out the reports while Carlos returned Jorge and I to the general population. At least the staffers were being more attentive. They knew this was their fault, even if they weren't held accountable. It was a long day.

When Mom came at 5:45 to pick me up, Mike was waiting for her in the lobby. He took her back to his office. She came out a little later with the report and a stressed face. She barely looked at me until we got home. It took restraint for her to not start yelling at me, I could tell. I think she knew not to take Mike's version of events at face value. She got the letterboard and had me sit in our spelling space, a small desk in a small study set aside for the purpose. \*\*\*\*\*

"Okay, tell me what happened today. I don't know what to think until I've heard your side of the story."

It took me a while to spell it out, but I was so grateful that I could.

"STAFF WAS GOOFING AROUND JORGE LEFT THE BUILD ING AND I FOLLOWED TO MAKE SURE HE WAS OKAY I SHOW ED CARLOS WHERE HE WAS"

Mom looked relieved.

"I knew it had to be something like that. I am so proud of you. You deserve a medal, not a report. I'll call Mike tomorrow and explain it to him. Is that okay with you?"

"NO PLEASE DONT MIKE DOESNT GET ME HE WONT BELIEVE YOU JUST LEAVE IT BE"

"Wow, okay. I guess I get it. What this tells me though is that we have to come up with a better situation for you. I wish I could snap my fingers and a magical perfect place would appear."

She held up the board for me to respond.

"MOM YOU KEEP LOOKING I AM SKEPTICAL FOR NOW T HE MAGICAL PLACE IS RIGHT HERE" I knew that would make her feel better. Her burden and mine are yoked together. We sat in our study space and our bodies and heads gently leaned together.

#### Ann the Lifeguard

My first day at Upward Bound was like a Kafka nightmare. Instead of waking up as a giant insect, I was a little girl surrounded by alien creatures. I couldn't say this out loud. It's so politically incorrect. Not to mention horribly unkind. Each one of these people is loved by somebody. God loves them. They scared the shit out of me. Imagine a room full of misshapen young men, not one of whom can walk without lurching. Several were in wheelchairs. Some could speak in words, although to call it conversation would be a massive overstatement. Some were completely silent. Most fell somewhere in between.

I go to college up in northern California and was home for the summer. My parents insisted that I get a job, although god knows I worked super hard all year and deserved a break. My dad actually said, "Welcome to adulting. There is no summer vacation in real life." Yeah Dad, you try keeping up a full load PLUS a job at the bookstore PLUS being on the intermural swim team. A regular job seemed like a piece of cake to me. I'm a psych major so I figured I might as well do something I could put on my resume, rather than Panera or Starbucks or some shit like that. I googled special needs summer program. There's not much in my area, but Upward Bound wasn't too far away. I went down there to put in an application. Jesus, you'd think I was the savior of all mankind the way the director mooned over me. It was creepy but not pervy if you know what I mean. The guy's name was Mike and he reminded me of the nerd with the emu in the insurance commercials. Kind of over earnest, over enthusiastic, super obsessed with the place. He wore cheap office clothes that made me think he doesn't make much money. I

understood right away that he needed people badly. I wanted to tell him to chill, that I could smell his desperation. But I sucked it up and was sweet and altruistic.

I told Mike that I was interested in working there because I had taken a psych class and learned about autism. That was a small exaggeration. The professor had mentioned autism briefly, the day he lectured on abnormal psych. If Mike wanted to hire me on sight, he now saw me as a must-have. I said basically yes before even seeing the place and its clientele. If we had done the tour first, I may have kept walking right out to my car. I was overwhelmed by the sights, not to mention the smells. But then Mike showed me the pool. It was pathetic as pools go, but Mike got all ecstatic telling me how much the clients loved their pool time. I made the mistake of telling Mike about swim team. He nearly passed out in excitement when I mentioned being lifeguard certified. It was decided. I was to be lifeguard when there was pool activity, and floater aide when there wasn't.

I wouldn't say the decision was impulsive, but neither was it well thought out. What kind of summer did I have in mind? Not one that involved a bunch of sad, disabled teens and adults. I thought at first that it was all guys, but it turns out that there were a few girls too. I had this impression from wherever that only boys had autism. Why is that? I went home and had a minor meltdown. All I knew was that I had no idea what I was doing. I got lifeguard training for a swim team project, but I barely had enough experience to guard a pool that had a few normal people in it. The pool at Upward Bound had one of those contraptions to lower a wheelchair person into the water. How do you even work one of those things? Would there be someone to show me what to do? How to tell if someone is drowning or just having an autistic spazz attack?

I was stressed out by the time I showed up for my first day. Mike met me in the lobby and introduced me to Carlos, a guy in his mid-20's who you could imagine had already spent

time in jail. Of course, this only proved what a racist bitch I was. A childhood spent in expensive private schools leads you to make some embarrassing assumptions in the real world. I gathered that Carlos was some kind of supervisor or head aide. Hopefully qualified enough to tell me how to deal with these "clients," as Mike told me to refer to the autistic and disabled people. Carlos surprised me with his competence and chill. He obviously knew what he was doing, but it was more than that. He made you feel more calm just being in a room with him. I can't tell you how many times over that summer when facing a gnarly situation that I immediately thought WWCD: What Would Carlos Do?

Carlos took me around the place. He rattled off protocols for things like taking clients to the bathroom, and cleaning up after them if you didn't make it in time. It was clear that I was to clean up male clients as well as the few females. There was the worn-out little kitchen, the laundry area, the patio and pool, and the locked cupboards with the craft supplies and toys. They used the mostly empty parking lot for basketball, and there was a scruffy little play area in the far back. The clients were all too big and old for that kind of play area. As Carlos explained how the schedule worked, I realized that they basically shuttled the clients in small groups from one activity to another, cycling them through the center's offerings, as pathetic as they were. It seemed sad and boring – the clients looked sad and bored at any rate. It took me a while to figure out that a lack of expressiveness was common and not a true indication of their satisfaction level. Many facts about the clients were only revealed when my vision cleared. It took a little time.

But I was talking about that first day. It still freaks me out how freaked out I was. I might prefer to forget it. But it occurred to me that I ought to have kept a journal this summer. I could use it as part of an honors thesis or something. So in that sweet spot between the end of summer

and the start of classes (senior year!) I'm going to try to get down what I can recall of this weird weird summer.

Before I could even form a cogent question, and I had about a million, Carlos mumbled something and wished me luck. He was gone. I felt like an uninfected person surrounded by zombies in a *Walking Dead* episode. I wanted to run, but I noticed two other staffers going about the breakfast prep. I could identify them by their bright purple t-shirts, like the one I was wearing. These Upward Bound tees were our uniform. On the back were several lines that were intended to be aspirational. Looking Past Disabilities, Looking For Possibilities, etc.. I'm not sure I saw the possibilities here. I clung to the two other purple t-shirts like a lifeline. I assisted them by lining up the little bowls of cereal for the clients to take. After everyone had some, the two staffers Chloe and Andy sat at different tables, so I sat at a third. It was relatively quiet while the clients ate. I was thinking that this might not be as bad as I worried.

The first session after breakfast obliterated my brief optimism. It was a gathering of everyone to go over the day's schedule, sing a freaking calendar song and recite a few facts like our city/state/country, who the president is and a recitation of the Pledge of Allegiance. The voices of Chloe and Andy were all I could hear. Most of the clients weren't capable of reciting the Pledge or singing the stupid calendar song. The ones that could probably manage it barely mumbled along, as if in a rebellious conspiracy not to participate in the babyish routine. I don't know anything about anything, but most of these people didn't strike me as retarded. They were out of control, their bodies didn't seem to follow orders, but there was a flicker of something that suggested that these guys might appreciate a morning routine that was more age appropriate. I guessed Mike and whoever else is in charge here knew what they're doing.

I was still in a low-grade state of panic when I had to take charge of a small group assigned to play a game of Cootie on the patio. Do you remember Cootie? You've got all these bug parts and you have to roll a die and get a certain number to put the bug together in the right order. I had four clients at my table. I didn't know their names or anything about them. One was a girl. They were obviously familiar with the game, although their grasp of the rules was fluid. One guy snatched up a bug body and started sticking legs in it before it was his turn. Another guy who suffered from verbal diarrhea kept rattling off the rules just as they appeared in the instructions. He knew every word by heart. The third guy just wanted to be told what to do, but his head looked like it was going to collapse from pingponging between the rules guy and the norules guy. The girl just sat there, quiet and complacent. She didn't make a move towards the game pieces. I tried asking their names. Verbal diarrhea guy switched his word track to naming. The clients at our table were identified rapid fire. No-rules guy was Ben. He would keep getting out of his chair to jump up and down. I spent half the time asking Ben to sit back down before I just gave up. Head imploder was Isaac, who was black and had dried drool on his t-shirt. Quiet girl was Emma, and I got the impression that the guys were in awe of her. The guy with all the words and names was Drew. He also rattled off everyone's birthdays.

Drew suddenly spit out at me: "What's your name? When's your birthday?"

"I'm Ann," I said, "and my birthday is May 11."

"May 11," repeated Drew.

He never forgot anyone's birthday, as I came to realize. Cootie was forgotten, however.

With a few minutes left of the session, I suggested that we all make the weirdest bug we could.

This is probably what made me think of Kafka. Ben sat down for this, but Isaac seemed overwhelmed by too many options. Emma put together something almost pretty. Drew chattered

nonstop until I wanted to scream, but there was already enough screaming going on. I got through the morning somehow. My stomach was too nervous to eat lunch.

The first session with me lifeguarding the pool came that afternoon. I had no idea what to expect. For one thing, it hadn't occurred to me that the act of getting twenty disabled adults into their bathing suits, along with their towels, goggles and sunscreen, was a time-consuming logistical challenge. It took virtually the entire staff to facilitate it. There were plenty of people around. I didn't have to worry about being the only pair of eyes on the group. Carlos appeared – thank God – pushing a surprisingly handsome guy in a wheelchair. Carlos called out to Andy to help him load the cerebral palsy guy with movie star looks into the wheelchair-lowering contraption. I was so relieved to see Carlos get in the pool with Tom, the lovely fellow. I'm not likely to forget that name. Several other staffers got in the pool too. So I'm not responsible for the bodies in motion. I'm just here in case of an actual emergency. That's even worse, in a way. I never thought of myself as someone I'd call in an emergency. Would I even know what constitutes an emergency in a group like this? Once the small pool began to fill up with the funky bodies of the clients and the more conventional bodies of the staffers, I relaxed a little. I started to look more closely at people. Everyone – both staff and clients – had been a blur so far as I had been fighting fear and nerves. Now watching the clients move slowly and awkwardly in the water, they didn't seem as threatening or scary. I have to admit that I had some idea that super autistic people were aggressive, that they would try to bite me or lash out and hit me.

I still wasn't quite sure of my function at the pool. I saw Emma hovering – hiding – in the corner of the pool, nearest my high lifeguard chair. Her eyes were unfocused, swiped to the side. I had the feeling that she was watching me, even though she made no eye contact. I called out

something stupid, like "Having a nice swim, Emma?" She receded further into the corner. I was pleased with myself for having remembered her name.

Drew, still super-talkative and eager to please, called out, "She can't talk."

I said, "That's okay. I bet she hears me though."

I cringed at how lame I was around these poor, odd creatures. How do I talk to someone who can't talk back? Is this girl so retarded that she can't understand what I'm saying? I realized that the clients were not a homogeneous mass of dysfunction. They varied a lot in how capable they were and in what ways they were capable. Stealthy Emma in the corner – who was still staring/not/staring at me – maybe couldn't speak, but she was quiet and gentle. It seemed like she was paying close attention to everything, even though she didn't show it. Hyper-verbal Drew, who memorized dates and had fewer physical issues than most of the other clients, looked like he had trouble with impulse control. I wondered if I would get closer to understanding these poor people over the summer. It's a lot different to sit in a lifeguard chair feeling responsible for all these autistics than to read about the disorder in an Abnormal Psych textbook.

The session in the pool was over in a heartbeat. It took them so long to get ready, and even longer to dry off and get dressed again, that the actual time in the pool was short. I felt like I should be helping the other staffers with the task, but I slipped away to get back into my own purple t-shirt and khakis. The thought of dealing with the wet swimsuits and naked bodies gave me the willies. No one seemed to notice that I skipped out on the getting-dressed routine. Maybe it wasn't part of the lifeguard's job. Admittedly, this place didn't seem like it was a stickler for job descriptions. Watching Carlos in action was a revelation. He was so quiet and humble, but also confident and competent. He handled things calmly. When a client fell on the bathroom floor while being changed and cut his forehead, Carlos just went into a protocol and everyone

relaxed and did their parts. Watching him, even on my first day, taught me something about what leadership is. At college, student leaders were usually the loudest voices. If I were in a real crisis, I would look around for Carlos, or someone like him.

The rest of the afternoon went by pretty fast. I didn't feel comfortable about my performance that day, but at least my anxiety had decreased a little. Over the next couple of weeks, the issue of anxiety came to my attention. I know why I was anxious at first. Upward Bound was a strange, new place to me, and it was filled with strange, new people. But why were the clients so anxious? All they had to do was follow the simple daily routine of playing games and whatnot. It seemed like a permanent vacation to me. Sign me up. Yet stress and tension buzzed through the place like a permanent live wire. I tried to figure out why. I developed a couple of theories.

- 1. Autism comes with a side dish of anxiety. It's part of the disorder. Nothing to be done without drugging the person to oblivion. Which some clients were.
- 2. The atmosphere at Upward Bound was inherently stressful. Too many people in too little space. Autism exponentially magnified.
- 3. They don't like it here. They would prefer to be doing something productive and ageappropriate. Cootie and crafts as a daily diet are boring.
- 4. All of the above.

I fell into the rhythm of the place. It was sluggish and hyper, loud and verbally unfocused, the time passed in a blur and days lasted forever. I learned a lot of names, both client and staff, but I wasn't confident enough in my memory to use them. Plus I would be gone in August, so why bother. There wasn't much of a break in the day to hang out with the other staffers. I worked mostly with Chloe and Andy, and we chatted sometimes when the clients were

engaged in something that didn't require our hands-on supervision. Both of them went to the local community college. Chloe was studying to become a nurse. She was a first gen-er, the first in her family to go to college. She was driven, like she had something to prove. Andy seemed to be on the eight-year plan. His intention to transfer to university was more stated than felt. I had doubts that he would make it. Still, here we all were, and how judgey can you be about someone willing to do this work?

I was intrigued by Tom, the adorable guy in the wheelchair. At first glance, he looked like an actor or a pop star. I approached him thinking he would be bright and conversational, just stuck in a wheelchair.

"Hey, Tom. How are you doing today?"

Crickets. He looked at me. It was one of the saddest faces I had ever seen. His natural handsomeness couldn't mask a baseline of frustration. He made a tiny murmur. I saw that on top of his dysfunctional body, he was not able to speak. He wasn't as withdrawn as Emma, but he seemed reconciled to people not talking to him. One-way conversations are difficult to sustain. I made a few more comments to him – at him, really – before I had to go do something. My heart ached for him. Every time I saw him after that, I made a point of getting on his eye-level and saying something to him.

"That t-shirt looks nice on you."

"Are the others too loud for you today? Shall I wheel you over here where it's a little calmer?"

"Hey Tom, is this seat taken? Can I sit with you for lunch?"

I am no Florence Nightingale for sure, but a little bit of humanity went a long way with this guy. He had little facial expression, but I could swear that he brightened when he saw me. That's more than I can say about other cute guys I meet.

I also made an effort with Emma. Her mom told me that she liked listening to music, so I would ask questions about what bands she listened to. She couldn't answer in words, but I figured out that if I sang a little of something, she would respond in a way I could understand. Fingers in the ears was a sure-fire "No." Humming along or smiling was an invitation to keep going. I found her happy place when I sang a little "Yellow Submarine." She obviously loved the Beatles and knew all the songs. Her humming, as tuneless as it was, was right on point. I started listening to more Beatles in my off-hours so I could come prepared. It was fun watching her react.

One activity that I did not look forward to was the weekly trip to Target. It was a community outing intended to desensitize the adult clients to the hustle and bustle of the real world. I had my doubts. Mostly these junkets exposed our people to stares or averted eyes. No one ever bought anything. No one was allowed to, including staff. I couldn't even say to myself, "It's Target day – ugh – but at least I can pick up some deodorant." We just wandered through the aisles aimlessly in a clumpy line. You knew what we were at first glance. I wasn't embarrassed to be seen with the group. I was invisible in my purple t-shirt. I know this because one Friday I spied two old girlfriends from high school in the hair care aisle as our group passed by. They may have recognized me and chose not to have a big reunion scene right then. It's more likely that our ragtag cluster was below their notice.

I wouldn't have had time to chat at any rate. Half the clients were docile (drugged?) and required only herding. Tom, my glamor guy, wasn't going anywhere without being pushed. I

always tried to be his pusher because I liked to lean over his shoulder and make rude comments about people and products. I imagined that we had similar senses of humor. The other half had various behaviors that had to be monitored. One guy (Walter?) would make loud noise, shrieking barely intelligible words and phrases from his videos. You really had to watch him in the DVD section, where the triggers were so numerous that his voice took on even more panic and volume, alarming real shoppers. There were others who managed to wander away from the trail and disappear. This one big guy escaped the group every week. He didn't leave the store, thank god. But Target has a lot of aisles and I got a workout running around to find him. This guy, whose name is Jorge – I'm pretty sure – was always hovering around Carlos at the center, but Carlos didn't do the Target run, so the poor guy was more unmoored than usual. After a few Fridays of this, I realized that he was in the toy section, or en route to the toy section, every time. After that, he was much easier to find. I would spot him and keep an eye on him, letting him have a little autonomous time to do what he really wanted to be doing. Everyone deserves that. Still, quipping with Tom notwithstanding, Target Fridays were stressful and exhausting. The only positive thing about the field trips was that they chewed up half the day.

As much as I had been anxious about my lifeguarding responsibilities, I looked forward to pool time. I got to sit in my chair on high and it was my personal territory. Everywhere else at Upward Bound I was one of the lowest ranking staffers. I was just a seasonal hire, which meant that I got assigned the shittiest chores. Literally. I learned to breathe through my mouth and conquer my gag reflex. But at the pool I could lift my face to the sun and breathe in the fresh air. I had authority at the pool. I had a whistle and I used it. Guy running – scuttling really – on the pool deck? Tweeeet! Guy splashes Emma in the face? Tweeeet! One of life's greatest pleasures is giving orders and having them followed. After the first few weeks of being super serious about

the job poolside, I loosened up. I could even focus better on everyone's safety when I engaged with the clients from the chair. Going at it with Drew was easy because he kept up a constant stream of verbosity. But he was low-hanging fruit. I got satisfaction from getting the less verbal clients to react to me. I teased, I flirted. I made both clients and staffers laugh by making up outrageous "Pool Rules" and levying fines and punishments for breaking them.

"Okay, no blowing farts in the pool! Hey Tom, you're stinking up the joint! You're going to have to pay up! Carlos, bring that guy over here so I can give him thirty lashes!"

The atmosphere at the pool elevated along with my attitude. Clients and staff played spontaneous games of beachball water polo, with me as tyrannical referee. More staffers showed up for pool time. Mike the director, who hadn't said much to me since he hired me, stopped me in the hall.

"Nice work at the pool, Ann. Love the sass. Just make sure that it's safety first."

"For sure, Mike," I said. "Safety first is my middle name."

He looked puzzled for a second, then burst into a forced laugh. He soon added an additional session of pool time to the daily schedule to accommodate all the clients who wanted to go swimming. The newbies at the pool were the more sedentary clients, so it felt good to see them moving around. Sometimes I got into the pool with Tom when Carlos was busy. I even learned how to operate the ADA pool lift. I enjoyed holding Tom under his arms and swishing him around in the water. He was weightless in the water. His tight limbs relaxed and stretched out. He would sometimes close his eyes and I wondered where he went in his mind. Does he dream of who he might have been if cruel fate hadn't marked him out? Or was it just me who had those thoughts?

I went home in the evenings with a sense of satisfaction, also complete exhaustion. My mom would ask, "How was work?" in that same perfunctory voice she used to ask, "How was school?" when I was growing up. She didn't appear to be interested in long anecdotes, so I didn't offer any. Mostly, I couldn't figure out how to explain what I was experiencing to someone who hadn't been inside Upward Bound.

"Fine," I said.

There was a day when things went wonky at the pool. I had been warned that this might happen. I didn't want to believe it. Poop in the pool. You might expect this in a preschool swim lesson, but no one in my pool was younger than 18. I had read the protocol for this in the scanty handout Mike gave me at the beginning. When it actually happened, my instinctual response was by the book.

"EVERYBODY OUT OF THE POOL! RIGHT THIS MINUTE!" I tried to keep my ewwwww response to myself, but I may have failed. I gave my whistle a couple of authoritative tweets. I hopped down from my chair and started assisting the clients in getting out of the pool. There weren't enough staffers present at that moment to herd cats back to the dressing rooms, so I was in five places at once. Thankfully, Carlos came to the rescue, and I was relieved to see that he had Tom in tow. I wasn't shy about helping the guys in sensitive situations – I was immune to it by this time – but suddenly I was weirdly reluctant to be around Tom in his most helpless and vulnerable state. The actions required at this moment were very intimate. The only way for everyone to retain their human dignity was to establish a kind of dissociation. I had developed an extra-verbal/beyond verbal connection with Tom that made detachment impossible. This was puzzling, but I pushed it to the back of my mind. Poop was in the pool.

The job of removing the feces from the water was above my pay grade. Or, more accurately, below my pay grade. There is a whole protocol involving a massive amount of chemicals to rid the pool of bacteria. This was not my job, and the pool was closed for the day. I took the ladies to the girls dressing room and I dove into the fray of finding cubbies and clothes. I helped Emma and a few others disentangle themselves from their wet swimsuits and take a scrubby, hot shower to eliminate whatever was in that pool. I brushed out unruly wet hair and did some ponytails. Emma wanted a French braid. I knew that because I had my hair in a braid a couple of weeks before and she was intrigued with it. She kept putting her hands behind her head, but stupid me didn't get the message. Finally she took my hands and put them on her head. Duh. It had become a thing for us. Then the four other girls in the dressing room wanted French braids too. In spite of the surroundings, which were more run-down nursing home than girlish boudoir, the vibe was fun sleepover rather than post-pool-poop hose-down. I had come to value the level of trust and intimacy it requires to accept this kind of assistance. They, the disabled, were not the other. I was the other, and they had let me in.

The summer speeded up. I looked up and there were July 4th decorations on the rec room walls. I looked up again and it was August. The July 4th decorations were still up. I went to Mike and asked if I could take them down, put up something more Augusty. He acknowledged my initiative in his smarmy tone, and pointed me towards the closet where they kept big plastic bins of holiday stuff. I enlisted the help of Emma, Drew and some other clients to take the flags and fireworks off the walls. They were unaccountably excited about this chore. Drew rattled off his astonishment.

"We're not supposed to touch those. We're not supposed to touch those. We're not supposed to touch those. Only staff do decorations. May 11."

"Yeah, that's my birthday. I got permission from Mike to deputize you guys, no worries hon."

I hadn't actually asked Mike, it hadn't occurred to me. Judging from the decrepit condition of the paper decorations, I didn't see how the clients could do a worse job than the purple t-shirts. I cranked up some classics on the rec room speakers. Beatles for Emma, Beach Boys for Tom, Taylor Swift for me. The Beach Boys seemed like an odd choice for Tom. I've never met his family, so I don't know if the love of California surf music came from them. One day I had been goofing around with Andy, joking about being a rare native of L.A., and I broke into a verse of "California Girls." Tom was nearby and he nearly spasmed out of his wheelchair. I asked him if he liked the Beach Boys, and he made his go-to guttural noise that I had come to recognize as "yes." Everybody knows that Drew is a movie nut – along with birth dates, movie opening dates are a verbal tic for him -- so I threw in some John Williams. Carlos joined us, along with his faithful shadow Jorge. They like hip-hop. We're not supposed to play personal music here, but once I had caught Carlos sharing his earbuds with Jorge, and I could hear the thumping bass from where I stood. The clients really liked music it seemed to me, and that hot August day in the rec room, I wondered why Mike didn't use it to soothe the savage beasts rather than forbidding it.

When the Beatles were playing, Emma went into a dreamy sort of trance. She stood facing the wall and swaying. She rejoined us once "Hey Jude" was over. Tom didn't have much facial expression at his disposal, but a certain light came into his eyes when I played "Wouldn't it Be Nice." I couldn't help myself – I grabbed the arms of Tom's wheelchair and wheeled him around in circles like we were at a high school dance. Tom threw his head back and joy emitted from him like sun breaking through clouds. His slender arms, usually held captive in his lap,

scrunched up in a cerebral palsied cramp. Instead of reminding me of his disability, the awkward gesture exposed the depth of emotion that was trapped in his stiff body. The crush I had when I first saw his splendid face came roaring back to me as a real thing. The idea of love, the need for love, the practical reality of love, didn't seem incompatible with a wheelchair and an uncooperative body.

Drew kept up his barrage of words and birth dates, but when the theme from *Star Wars* came on, he ran around the room with his arms open like wings, going "bew bew." It occurred to me that Drew had all the spoken words that were denied Tom and Emma, but he was the least mature of them. His wall of words kept him trapped, not allowing him to get beneath or above the empty, repetitious words. Being able to speak was not Drew's superpower. It was his kryptonite.

We got all the paper flags and patriotic stuff off the walls and packed them up. I surveyed the other bins with Carlos and Emma. Carlos pulled out a palm tree and softly said, "Tiki time." Brilliant. I put on some Bob Marley, which animated even slothy Jorge. We scoured the bins for anything vaguely tropical. Carlos got Jorge out of his chair to hang one of those phony fishing nets across the wall. Jorge started giggling for no apparent reason. It was infectious. So corny, but I put on "Don't Worry, Be Happy." It's got that island rhythm. We were all kind of dancing. I looked around at this funny little party and marveled at how much fun I was having. I thought of the last party I had been to up at school, where I drank too much and fretted about how popular I wasn't. This was better.

When we had masking-taped every palm tree, tropical fish and toucan to the walls, we stood back and surveyed our work. It could not be said that we transformed the ratty rec room into an island paradise. There aren't enough paper parrots in the world to pull that off. Also, the

fact that clients were involved meant that rules of order and proportion were not strictly observed. One wall had coconuts clumped together in isolation and were too close to a school of sharks and Nemo fish. Some areas had no decoration at all. The imperfections were what made it perfect. You could tell that the clients had done it, and that was more pleasing to the eye than symmetry. If the walls weren't enough to convince you of the rightness, look at the bliss on Emma's face. Look at Jorge, still giggling because Carlos is teasing him about the coconuts. Tom couldn't help with the decorating, but his face and body were scrunched up in a nonverbal expression of enjoyment. Changing the script on who could do a certain task had woken us up. The energy we generated had just started to fade when Mike came in. On the speakers just then, a Lizzo song came on. Mike looked furious, but you could tell that he was trying to maintain his benevolent leader demeanor.

"What's going on here?" he said with a strained voice.

Drew piped up, god bless him.

"It's tiki time! It's tiki time! It's tiki time! It's tiki time!"

Mike prides himself on being the Upward Bound party planner, although he sucks at it.

You could tell that Mike resented there being an unauthorized bash. He kept his voice under control as best as he could.

"Ann, could you please turn off the music? The rest of you go out to the patio, there's a craft activity waiting for you. Ann, can I see you in my office?"

Carlos wheeled Tom out of the room without looking at me. Tom kept his head turned in my direction as long as he could. He had an adorable face of concern, like I had gotten into trouble on his account. He wasn't wrong. Emma and Drew followed. They had dumb, defeated looks on their faces. I followed Mike down the hall to his dingy office. I knew he was mad, but I

wasn't worried about getting fired. The summer was almost over and Mike, as always, was short-handed. He spoke to me with his wussy version of authority.

"I'm curious as to how you got your personal music on the loudspeakers, but you can show me later."

I suspected Mike was a luddite, but could he really be that ignorant about how phones work these days?

"You don't have much familiarity with our clients, so let me fill you in."

He proceeded to tell me how their whacked-out sensory systems made it inadvisable to play music because they get over-stimulated.

"They get too excited and could harm themselves or others. They could even lash out at you, and I am responsible for your welfare."

What about their welfare? What about their quality of life? Where is fun and joy to be found in their lives? I kept this to myself.

"It's also not okay to give them tasks of a practical nature. The risk of failure is too high."

I had to respond to that.

"I'm sorry, Mike. I know you have all the experience. But it looks to me like the clients are bored out of their minds. They seemed to enjoy doing something productive. I bet there's a lot of things they could do around here that would be satisfying to them and helpful to you."

The smug look he gave me was the very picture of misogynist patriarchy.

"I guess you don't know about a little thing I call insurance and liability. I'll tell you all about it if you come back next summer."

Mansplaining gauntlet thrown. Did he honestly believe that there could be liability issues related to taping decorations to the wall? It occurred to me that Mike's rigid rule system was his

disability. Otherwise, I couldn't understand how someone could work here for years and not have a clue about the people in his care.

As the day approached that I had to return to school, I felt an impending loss. Like when I went to camp, and when it was over, knowing that I would never experience those people in that place ever again. It was hard to remember how anxious and stressed I felt at the beginning of the summer. The disaster I feared might occur at my pool – drowning, autistic riot, Tom's wheelchair falling in – never materialized. I made friends here, not just other purple t-shirts but clients, too. Some clients will soon slide from my memory. Others will become permanent installations. Emma's quiet knowing, Drew's efforts to please, Tom's lonely beauty. I was confused about how I felt about Tom. Was I superimposing my empathy for him onto him unfairly? Did we really have a compatible connection, or was I kidding myself? I had no clue about his level of intelligence, but I had read the most imperceptible signs as sparks of understanding. If I am right, what happens to him? Will there ever be a way for him to tell us – tell me -- what is going on with him? It was like quicksand, these imponderables.

I recalled an incident from elementary school. There was a very autistic kid in my fifth grade class. It was clear to all of us that there wasn't much point in the kid being there. He wasn't capable of the work we were doing, so he sat in the corner of the room with an aide, doing something simple. He made weird noises when he got frustrated and he got frustrated easily. The aide would take him out when he got too disruptive. Then we wouldn't see him for the rest of the day. The time he would spend in class got shorter and shorter. Seriously, what was the point? One morning, he walked into the classroom and the first thing he did was to grab a chair and hurl it up towards the ceiling, shrieking all the while. I was sitting at my desk in the path of the chair as it came down along with a chunk of ceiling. A chair leg glanced off my

shoulder, hitting me hard enough to make a bruise. The ceiling material made a direct hit on my head. The chunk was light and didn't hurt much, but I was startled and let out a scream. The teacher came rushing over while the room erupted in noise and activity. The boy's aide was told to get him to the office. The teacher knelt to assess me. I really was okay, but I was crying. They took me to the nurse's office and made a big fuss over me. My mom came to pick me up and I got to watch TV all day. The autistic kid didn't come to class after that. No one talked about it, but I think we were all relieved he was gone. I'd like to go back in time, knowing what I know now. I probably couldn't have helped that kid, but maybe he wouldn't have been so anxious if someone had been nice to him.

My last day arrived before I was quite ready for it. Another of Mike's misguided rules was that no pictures were to be taken of the clients. He took the issue of privacy seriously, but he took it a couple of steps too far. If clients had a good time on a field trip, or made friends with someone, there was no record of it to keep or cherish. Now I was leaving, and I somehow knew I would never come back. I desperately wanted something to remind me of my favorites. I wanted a picture of Tom's beautiful face. I broke the rules. One by one, over the course of the day, I pulled Emma, Drew and, finally, Tom into an unseen corner to take some selfies. Candidly, they were awful. My beloved clients aren't photogenic under the best of circumstances, and I looked puffy and upset. I will never post these on Instagram, not because they are unflattering, but because they are too real for vapid scrolling. Anyway, to post them would only be one of those self-serving plays for praise — look at what a saint I am. Humble brag annoys me and I am not a saint. I will keep these photos in a file and open it when I need a booster shot of perspective.

So I've done what I set out to do. I've taken stock of my summer. I leave to go back to school tomorrow. I have a feeling that there are going to be consequences that I can't foresee

from this close range. That's okay. One thing I'm thinking about is taking a speech pathology class in the fall. I know of one client at Upward Bound who is supposedly able to communicate by typing. I didn't see him do it, but I'm really interested in the potential. Possible career path. I'm having trouble finishing up my packing. I keep looking at the best picture I got of Tom. His eyes are closed in most of them. He literally looks like an angel. Saying goodbye to him on my last day was anticlimactic, but I knew enough by now to expect that. I knew also that my absence would be felt. I may not have access to his words, but his eyes told me. I'm reminded of that phrase they use in memes: find someone who looks at you the way Tom looked at me the day we decorated the rec room and we danced to "Wouldn't It Be Nice."

## Tom the Movie Star

The burly care provider (Victor this morning) lifts Tom out of bed and places him with surprising gentleness into his chair. Tom takes his first pee of the day in the toilet. He tries to poop then too, because he'll be in a diaper for the rest of the day and he'd rather not make someone else have to deal with that. Tom has some use of his arms, but not enough. Until he was 12, his mom was able to lift him out of his chair. He didn't weigh much as a kid. He's an adult now, and taller. He has a small army of caregivers who help with one thing or another. They come and go in shifts. They also come and go. Tom thinks he'd have less turnover if he could chat and form bonds with them. The same CP that makes his muscles and joints stiff as concrete also freeze his face and mouth. He can't speak a word and can't express emotions. He has them, god knows he has them, but he holds even the most benign feelings inside like a well-guarded secret.

Tom's day begins. Victor wheels him out to the kitchen where his mom has cold toast waiting. Victor helps him get it to his mouth. Some days he feels loose enough to get a piece to his mouth himself, but today is not one of those days. Tom's mom and dad are divorced. His dad used to help schlep him around, but after Tom turned 18, his visits decreased. His mom works full time, and he knows she's looking for some kind of residential setting for him. She's done with the day-to-day chore of him. He doesn't blame her. Part of him even looks forward to some autonomy. But it's also scary. People don't realize that he can hear and understand everything said around him, so he has heard a lot of negative comments about how people like him are treated out there. He can't fight back. He literally can't stand up for himself. He can't speak to

any abuse. He can only hope that no one takes advantage of his vulnerability in order to work off their own pain.

Victor waits outside with Tom until the little yellow bus from Upward Bound arrives. The act of getting him on board takes a long time. The driver puts out the little red hand on the side of the bus that tells passing drivers that they are supposed to stop for the disabled person boarding. Very few cars actually stop, but Tom thinks they slow down a little. The driver comes around – it's almost always a nice lady named Betty – to open the door at the rear and lower the lift. The lift is excruciatingly slow both ways. Tom doesn't mind for himself. He's got nothing but time. He feels bad that able-bodied people have to sacrifice some of their precious hours on the planet to help him live his less-than-precious life. These are his thoughts as he, Victor and Betty stare at the lift as it creeps along. Once he's on the bus and Victor wheels him into his spot, Betty locks down his chair and gets back in the drivers seat. Tom is always picked up first, for reasons that are not entirely clear to him. He sits patiently as the other five clients in his area are gathered. How else is he going to sit but patiently? It takes an hour and fifteen minutes to reach Upward Bound this way, whereas it takes his mom about ten minutes to drive there. Tom doesn't mind. At least he's out and can look out the window.

There's no sense in describing what Tom does all day in any detail. They wheel him around from one activity to another. He can't really participate in any of them. He just watches. Sometimes the staffers forget to move him and he just sits by himself until someone spots him. It's a little demoralizing, but Tom decided long ago that feeling bad about his predicament only made him more miserable. Tom is particularly sensitive to any changes in routine or personnel, either at home or at Upward Bound. He mostly looks forward to these modifications, as the novelty gives him something to think about. His inert body also responds to change. He twitches

a little, and his mouth makes a sideways gaping grimace that looks like a drunk person yawning. The problem is that his caregivers, including his mother, interpret his involuntary movements as a negative response to change. So they attempt to minimize any alterations in his routines and caregivers. As if the monotony was comforting. If he were ever blessed with some means of communication, the first thing Tom would tell them is, "Please, for gods sake, mix it up! Take me somewhere I've never been! Show me a movie I've never seen! Introduce me to strangers!" But until that glorious day, he has to appreciate any little spot of newness where it arises.

Today turns out to be one of the most precious days of novelty that Tom has experienced, and no one can shield him from it. It's summer, and there's always some staff turnover in summer. College student part-timers go home for the summer break, while kids who attend college elsewhere come home and need summer jobs. So it's common to come in and see a new face. Today a girl named Ann appeared. Mike seems excited to have her. He introduces her to the other staffers as the new lifeguard. Time in the pool is a big part of the day during the summer, so this is good news. Tom wonders why Mike doesn't introduce the new girl to the clients too, but he's not surprised. Things are rarely conveyed or explained to the clients, as if they don't really need to know what is happening in their universe. Tom is watching Mike hand off Ann to Carlos for a tour and some training. She looks overwhelmed but is trying to appear confident. Tom can always tell when a staffer is a newbie to the disability game. They are afraid to look at us straight on. They are not so much scared of us, Tom thinks, but they feel inadequate as to know what to do. This usually annoys Tom, but he feels optimistic that Ann will work out.

Tom waits patiently through the morning activities. Swim time comes after lunch. The sun doesn't hit the pool until noon, and Mike doesn't use the pool heater, so even in summer it's chilly in the morning. Tom's twisted body prefers warm water, but even at a lower temperature

he finds relief from the rigidity of his muscles. He has to wait for Carlos to come get him and change him into his bathing suit. Everyone is already in the pool when Carlos wheels him out. Andy helps Carlos with the lift that lowers Tom into the water. It is as excruciatingly slow as the bus lift. Tom sees Ann up on the lifeguard chair, looking cute and athletic in her Speedo one-piece. She is staring intently at the lift operation. At least Tom knows she has noticed him. He would be flattered, but that would be ridiculous, and she is clearly trying to make sense of the machinery that gets a wheelchair person into the pool. Carlos goes into the water with Tom and holds him up by his armpits. Carlos uses as light a touch as possible, to give Tom the feeling of freedom in the water. Tom forgets the new girl as he floats in weightless calm. He is aware that there are others in the pool, but Tom has an advanced ability to shut out the noisy, bumptious world. He can hear Drew showing off for Ann with all his words, but he is especially good at tuning out Drew's verbal repetition. Swim time is over too soon. Tom endures the chore of getting back in the chair and dressed again. He hopes Ann feels good about her first day.

Tom thinks about Ann at home that night. Tom sits in his chair while his mom watches TV. He has tried to convey to her that he really likes sitcoms from the 70's and 80's, like *Golden Girls* and *The Mary Tyler Moore Show*. He thinks she's selective about what she understands, because she exclusively watches true crime shows. He always knows who did it five minutes into the program. Good thing he can't spoil it for her. He fantasizes about what it would be like to have Ann for a girlfriend. He doesn't usually allow himself to indulge in such imponderables. It's painful to dwell on something he can never have. In this situation, strangely, he can't help it. He imagines that he saw Ann looking at him, not just while he was being laboriously lifted in and out of the pool, but afterwards too. He imagines that she looks at him the way a girl looks at a boy she thinks is cute. He's been told that he has a nice face, but he always hears "...for a guy

in a wheelchair" after it. He feels as if the chair is less primary to Ann. He knows he's being delusional, but what if it's just a fraction of a bit true?

Alfredo arrives. It's his shift to bathe Tom and get him ready for bed. The routine takes about two hours. When he was small, his mom and dad performed the job as a tag team. Back then, his mom used to read to him in bed. She stopped a long time ago. Tom thinks she started to believe what his teachers said about him being retarded, and she figured there was no point. Tom thinks she should have known better. Maybe she just got tired of everything. Tom knows something about that. After Alfredo gets him situated for the night, he smiles and says, "Sweet dreams, man." Tom smiles/grimaces back, or imagines that he does. That night, he actually has sweet dreams. Either Alfredo has supernatural powers, or Tom finally has somewhere beautiful to go.

Tom is in a pub in England, or so it seems. He's dressed in country clothes and is wearing a tweedy newsboy cap. He is chatting with some older farmer guys when the old oak door flies open, letting in a gust of wet, cold wind. Into the pub burst three young women, laughing and huddling together. It's hard to see them at first with their jackets and scarves. They peel off their outer layers as the crusty men in the pub steal glances. One girl heads to the bar to get their drinks. She squeezes in between Tom and the sheep farmer next to him. She leans way over the bar and says, "Three pints of Guinness, please." Tom can smell the rain in her hair. She is just turning to give him a big smile, when

"Good morning, sleepyhead," Victor nudges him. "You look happy to see me."

Tom manages to make a kind of gargle sound in lieu of a laugh.

Later that morning, Tom gets wheeled to Ann's table on the patio for a game of Connect Four. He usually checks out during an activity like this. He has a little repertoire of fantasies that

help him get through the day. He gets his scenarios from bits of shows and stories he's exposed to. Sometimes he's the handsome young doctor at the big city hospital. Sometimes a firefighter, sometimes a baseball player. Girls – nurses or groupies – swoon over him, but always from a distance. He recalls his dream from last night, and wonders where his subconscious came up with that one. That was the closest encounter he's had with a female in his fantasy stories.

Today, at Ann's table, he can't summon any of his usual escapes. Ann keeps talking to him.

Talking at him, more accurately. He knows she's new and doesn't know any better, but he's not accustomed to people addressing him so much. It's obviously awkward to keep talking at someone who never answers and who doesn't appear to hear or understand you.

"Hey Tom, which row should I put this bad boy in? Drew is kicking my butt here."

"Tom, if you move three inches to the left, you'd block the sun from my eyes."

Tom wonders why she doesn't move his chair herself if sun blocking is her objective, then he realizes that she's kidding. She's teasing him. Nobody ever teases him. It's like there's this invisible line of disability, where if you're on the wrong side of it, not even the bullies will make fun of you. You're so far gone that there's nothing funny about it. Having Ann tease him is a weird, new sensation. At first he doesn't like it. But she keeps doing it. The hour session on the patio flies by. He realizes that he was engaged at the table the whole time. Ann may have no experience with people like him, but maybe that also means that she doesn't know the rules and doesn't know when she's breaking them. He decides to keep an open mind about it.

Tom's chair is parked on the periphery of the parking lot while clients are playing basketball. He's not really watching. He's mostly trying to control his head and neck muscles so that he can get some sun on his face. Suddenly Ann appears from behind him, bouncing like the basketball. She's brimming with energy as she crouches on the asphalt and looks up at him.

Another new feeling. Tom realizes that people are almost always looking down at him. Even when seated, Tom is physically shorter, and typical people sit straighter and taller. Ann's sacrifice of kneeling is comforting and a little thrilling, even though Tom is certain that the action was unconscious on her part.

"Hey Tom, are you going to hit a three-pointer from here?"

Tom is ready for her joke this time. He wants her to see that he gets it. All he can manage is his grimace/yawn move with a kind of low-pitched cat sound. Her face lights up.

"Oh, you thought that was funny, huh?"

Oh my god, Tom thinks. I'm having a conversation.

After Ann has been at Upward Bound for a few weeks, Tom knows that he's not imagining things. Ann really does seek him out. He doesn't understand why. He has never been anyone's favorite before. He has so many needs and so little to give in return. The weird thing about Ann is how their interactions feel almost reciprocal. She tosses a little comment at him, and then she waits and watches. It's as if she can read the little twitches he is able to make. Most people don't have the interest or patience to focus on him like that. Not even his mother. She stopped really looking at him several years ago. He had a medical evaluation when he was 18. In hindsight he realizes that it was intended to determine whether insurance would pay for the physical therapy, speech therapy, and occupational therapy he had been subjected to his whole life. The school district and the Regional Center had been providing it up to now, but at age 18 everything goes away.

He's right there in the room when the doctor says to his mother, "I'm sure you're aware that patients with the spastic quadriparesis form of cerebral palsy have shortened life spans. Tom is not likely to experience any significant improvements in mobility or independence at this

point. You may want to start looking for a residential placement where he can be comfortable for the time he has."

The time I have? thought Tom. How much time have you got, doctor? Or you, Mom? How much time is the right amount? Tom is not as concerned about his longevity as he is about quality. He wants his life to be more than a long (or short) slog of painful dependence and helplessness. But there is no cure for what ails him, and the powers that be determine that there is no point in throwing away any more money for therapies to help someone who can't be helped. It was at about this time that his mother stopped looking at him. A part of her detached, as if he were already in some institution or group home. She had already said goodbye, maybe I'll see you on Sunday. Tom is used to living within himself, but he still misses her.

Tom has always been neutral about the weekly field trips to Target. He likes being out, but every Friday is the same, and every routine can become routine. That is, until Ann joins the odyssey. That was one of her jokes.

"Wow, we really put the 'odd' in odyssey," she mutters in Tom's ear as the ungainly group shuffles through the store. She had to prove herself before being allowed to take part.

Mike trusts Carlos, and Carlos trusts Ann. She makes the outing more fun, not just for Tom, but for all of them. She insists on pushing Tom, which makes him feel special. He so often considers himself a chore, but she acts as if pushing his chair was a stroke of luck. She pushes while bending over his head. She whispers subversive little comments about people and things they see.

"Who needs a mountain meadow in their washing machine?"

"So should we get the pink champagne or the Manischewitz for tonight, dear?"

"I think the pajama bottoms are a rockin lewk for a Target Friday. Let's both wear them next week."

Tom scrunches up in rigid-limbed delight when she cracks him up like that. Ann likes to put her feet on the back of the chair and ride along with him. One Friday, Jorge wanders from the group. This is not unusual. Ann volunteers, "Tom and I will fetch him, never fear." Ann takes off, pushing Tom. She leans over him and says, "We both know he's in the toy section, right? Let's take the long way and give him a minute of self-determination."

Ann pushes Tom fast down the aisles that are deserted on a Friday morning. Office supplies, party goods. She gets a full head of steam going, then puts her feet up on the chair. The two of them fly free down the aisle. Tom is in a state of joy. He never gets to do anything naughty, and the speed! Ann makes a wide, fast turn around the store and comes to a screeching halt next to Jorge, who is predictably in the preschool toy aisle.

"Hey Jorge," she greets. "How are Mr. and Mrs. Potatohead?"

Jorge, being nonspeaking, doesn't respond. But then, he's in a Potatohead-induced trance.

Ann gently tugs him away, and the three of them take their time finding the rest of the group.

Tom looks forward to pool time. After she finds her sea legs, Ann makes the pool her monarchy. She jokes around, while staying vigilant about safety. Carlos is in the pool with Tom when he is called away. Ann offers to take his place so Tom doesn't have to get out, too. Tom feels Ann's surprisingly strong arms slip around his armpits to hold him up. She floats him all over the pool, and somehow creates a kind of conga line flotilla of funky swimmers, Tom at the head. Tom revels in the spontaneous game. His activities are always planned and polite. Ann makes him feel like a whole person, not a chair. He thinks about her when he's at home, and he is always on the lookout for her when he's at Upward Bound. It's the happiest he's ever been, no

question. The only thing that darkens his heart is the awareness that she is only there for the summer. She will go back to her college in August.

Tom begins to develop a new fantasy. It starts as a vague idea and gathers details as he goes. His hope is that this story will help sustain him after she is gone.

In this fantasy, for the first time, Tom is in the chair. All his previous scenarios have him strong, tall, and able-bodied. Ann is just like Ann, but she's not in college anymore. She has a cool job and, whatever it is, she works from home. Home is a nice apartment that she shares with Tom. She does some caregiving of him, early in the morning and at night. Together they have organized a program for him that fills his day with positive action. She assists Tom in finding funding for therapists, because the speech, OT and PT did actually help him. The best part of this shiny, new life is that they found this smart college kid who comes in for a couple of hours every day to read to him. This guy takes Tom on walks and talks about trees and insects and other interesting things. The guy (Tom calls him Thomas in his fantasy) is working on a project at school, building a device that would enable Tom to communicate by blinking his eyes. Tom has heard that Steven Hawking had something like this. Tom and Ann have already been using eyeblinking as a basic means of communication. One blink for yes, two for no.

"Do you love me?" she asks, already knowing the answer. Tom blinks once.

When he opens his eyes again, Tom is looking up at Victor's benign face.

"Hey handsome, time to rise and shine."

Tom's new fantasy is less idealized than the doctor or firefighter ones, but it's perfect. He feels like more of a hero than before. Then it hits him why this fantasy scene is so important. It's actually feasible. He'll never be a firefighter, he could never become a doctor. And Ann will most likely never be his real-life girlfriend. But he is actually capable of controlling his eyelids.

He tests it out when Victor is helping him eat breakfast. Aides have a way of asking questions of a nonspeaking person, knowing they can't answer. Tom decides to try an experiment. When Victor asks a facetious yes-or-no question, Tom responds by blinking as loudly – as obviously – as he can.

"Still hungry, my man? Want another piece of toast?"

Tom works hard to angle his face toward Victor and he blinks as big as he imagines a clown would do, twice. He realizes that Victor isn't really looking at him. He tries again – blink blink – but Victor has already turned to get the toast. Okay. It's proof that people don't really look at one another, or maybe proof that we are dependent on the spoken word to communicate. Tom decides then and there that he is going to practice his blinking at every opportunity until it becomes automatic. He'll work on consistency and response time. If he keeps doing it, someone will eventually notice. Won't they? A speech therapist could work out a system for him, if he ever got taken to a speech therapist again. The thought of this deflates Tom. But he commits to blinking, because what else is he going to do.

Tom blinks his way through the day at Upward Bound. He moves his head, too, as best he can, to call his attention to his face. This, Ann notices.

"Are you showing me your best side, you handsome thing? Are you ready for your close-up?"

Tom blinks twice. She doesn't get it. He blinks again, but she's up and moving now and not looking at him. This may be harder than I thought, thinks Tom. He keeps blinking at every yes/no question lobbed futilely at him throughout the day. He notices how often people talk at him this way without even trying to look for a response.

"Are you all done with your snack, Tom?"

"You wanna come sit at my table for craft time, Tom?"

"Did someone leave you all alone in here, Tom?"

Two blinks. One blink. One blink.

As much as Tom has spent most of the summer thinking about Ann, his thoughts are now taken over by the thin slant of sun that has appeared. He sees the light of communication in the darkness of his day. He just needs someone to notice. He naturally, naively thought it would be Ann. He even worked it into one of his fantasies. They would be at a table playing Sorry when she would playfully ask him, "Should we move this guy or that guy, Tom?" And he would blink once and she would catch it. "Wait, what? Did you just blink on purpose?" Tom would blink once again, and he'd be off to the races. Ann would show everyone what he could do. She'd demonstrate for Tom's mom and his mom would cry. She'd find a therapist to develop the skill. He'd finally get the chance to learn something, study something, get his GED. He'd appear at conferences, maybe write a book. Tom focuses hard on this, his best fantasy, that isn't so fantastical.

The time is getting closer to Ann going back to school. She still clearly focuses her attention on Tom, but not in the way he needs her to. He is good at tracking people's emotions, thanks to being so still and so quiet himself. Ann genuinely likes him, although he is hard-pressed to understand why. But he senses a slight detachment, not just from him, but from her whole Upward Bound experience. Part of her is already back in her dorm room and her classes and her friends. And boyfriend? She never mentioned a boyfriend, but that doesn't mean there isn't one. It's like a slow goodbye. Tom doesn't blame Ann for not picking up on his blinking, but it helps him in detaching himself. He's going to miss her, but he's finally got a job to do, and apparently he's going to have to do it on his own. Blink.

August wends on. It's hot and the pool feels especially good. Ann isn't as much fun as before, so some of the magic has drained out of it. As Tom floats around held up by Carlos, Ann looks out at the sea of broken bodies, looking for potential disasters. She sees Tom, but she doesn't see the catastrophe in his eyes. He turns away as Carlos flips him on his back. She continues to scan blindly. Mike doesn't plan going-away parties for staffers, much less for summer people like Ann. People say he underplays staff departures so as not to upset the clients with impending loss and change. Mike needn't worry. Upward Bound clients have lost more aides, therapists and caregivers over their lifetimes than Mike can imagine. Tom certainly has. Losing Ann is different, but not unimaginable.

The day finally arrives. Tom thinks it would be like a Hollywood movie for Ann to have an epiphany about his blinking as she was heading out the door. Too much like a movie. He tries not to let his disappointment spoil his day. It makes him feel special when Ann conspiratorially takes him to a quiet spot to do a selfie. Phones aren't allowed, and neither are unauthorized photos of clients. It's not like Mike is going to fire her today. He feels a little less special when he sees her taking other clients out for secret selfies. And he'll never see his picture with her anyway. It's not like Ann has his mother's phone number to text it. Tom does his best to get through the day. When the time comes for her to leave, she seeks him out. She crouches down and looks up into his face.

"Oh Tom. I'm so glad I got to meet you."

Blink.

"I'm going to miss you, more than you can imagine."

Blink.

"I hope you will be happy. I'll be thinking of you."

Tom doesn't bother blinking again. He can tell that Ann is emotional, but he has no other means to express himself in return. He feels his stiff body withdraw into itself, making himself smaller. And then she is gone.

Everyone is busy then. Staffers see Ann off. Busses arrive. Tom's bus is always last, so he's left in the rec room by himself. Then Carlos comes in, apparently looking for him. Instead of wheeling him to a bus, Carlos takes a folding chair and sets it down in front of Tom. Carlos looks right at him.

"Tough day for you, buddy."

Blink.

"She's a nice girl. She likes you a lot. But that doesn't help right now, does it?"

Blink blink.

"Hey Tom, is something up with your eyes?"

Blink.

## Mike the Director

Mike gets into his grumbling Honda Civic and pulls out of the Upward Bound parking lot. He makes his breathing as slow and deep as he can so that the stress that rises from the rush hour traffic doesn't agitate him. Conquering frustration has been crucial for his job. There is nothing more frustrating than having to deal with an autistic man twice his size in full meltdown, behaving like a ridiculous but dangerous child. Even more frustrating is having to raise funds for the center. Some of the clients' families are well-off and willing to contribute, but it's never enough. He feels like he walks through life with his hand out, hoping a few dollars will fall in. Just like the filthy, unhomed man standing next to his car at the stop light. Not enough separates him from the ragged man on the median. Mike has a fancy title, but the salary that comes with it isn't enough to cover the bills.

He drives through McDonalds on his way home. He keeps meaning to get some healthier food in his fridge, but he's always too exhausted after work to cook. Any vegetables he buys end up shriveled and dried out, so he just stopped buying them. Even stoked by junk food, his 46-year old body isn't too fat, so he figures he still has time to clean up his act. He drives south, the houses giving way to apartment buildings that get gradually shabbier. He enters his parking garage and avoids the post that have left marks on his car that aren't worth fixing.

Mike gets his mail from the rusted cubby with the broken lock and uses the stairs so he doesn't stink up the elevator with his McDonald's. He knows he has to eat fast or the French fries will harden into their original chemical state. He sits on the brown sofa and clicks on the TV while opening the messy little packets of ketchup. Of course he gets ketchup on the remote,

because of course he does. He also gets some on his short-sleeve button-down work shirt. It was on its third day anyway. He finishes his Big Mac just as the local news is coming on. He's been on the news a bunch of times. That's something that his old high school classmates can't say. Every year, Upward Bound puts on a big fundraising event, and Mike manages to wrangle an aging TV star to host. The star is just big enough and he is just persistent enough to get at least one of the local stations to cover the event. He doubts that the coverage sells any tickets, but having Upward Bound in front of the public eye is always a good thing.

People are not necessarily drawn to a place like Upward Bound when they go to make a donation. The clients are mostly young adults with autism. If any of them were cute as kids, which is hard for Mike to imagine, they lost that years ago. Upward Bound is the kind of place that people are glad exists, so the autistic adults have somewhere to go. They also don't really want to know about it. Hence his difficulties fundraising. Hence him falling all over himself in gushing gratitude to the 80's TV actress who is willing to show up to his annual Fall Festival and have her picture taken. You can usually see Mike in the picture or in the background of the promo spot, but the actress does the interview.

Mike acts very cool during these brief moments of star proximity. He came to Southern California fifteen years ago with ideas of working in Hollywood. He knew he couldn't make it as an actor, even though he had played Uncle Vanya in a production of *The Cherry Orchard* at Western Kentucky University. He knew he had talent, but he was self-aware enough to know that he was not in possession of movie star looks. That didn't stop him from going to a couple of open casting calls that he found online when he first moved here. Those all turned out to be efforts to get him to sign up for an acting workshop, and he didn't have the money for that kind of thing. He believed that he had it in him to be a director, but he needed a shot. As the *Hamilton* 

lyric says, he's not going to throw it away. No shot has presented itself, at least not so far. He harbors a secret dream that one of his Fall Festival donors will be a producer who notices how well he manages the big event and will tap him to direct an episode of his Netflix series. Or Amazon, or AMC. It hasn't happened yet, but you never know. One of his clients had a dad who worked at the studios, but the poor man passed away before the client came to Upward Bound. Mike is always nice to the mom, in case she remarries someone in the industry.

Big Mac consumed, *Jeopardy* on. Sometimes Mike knows the answer and calls it out as the contestant buzzes in. It feels good to be right, but he wishes someone was there to admire him. He had a girlfriend for almost a year, but she broke up with him right before the Fall Festival two years ago. He knew it wasn't a forever thing, but he thought her timing was unkind. She knew how important it was to him, and it definitely threw him off his game that year. They didn't have much in common. She didn't like *Jeopardy* for example. Seriously, who doesn't like *Jeopardy*? She said it made her feel stupid. He probably made a mistake when he took her to Upward Bound for a tour. He hoped that she would be impressed with him being the director and voice of authority of the whole place. Instead, she was awkward and uncomfortable and couldn't wait to leave. He tried to look at the building and the clients with an objective eye, but believed that there was real goodness in the place. The clients looked weird and there were admittedly a couple guys who could get aggressive under certain adverse circumstances. There wasn't any real reason to feel fear. Everybody there needed to be there, including him.

Mike thought that Sharon could have had a more charitable attitude about it. She went to church all the time, didn't she listen? Mike's not that big of a Christian, but he figures that Jesus would love what he does for the disabled people under his care. In the same way that his autistic clients need a place to go, so does he. He had always had trouble finding a place to fit it. He was

bullied in school for looking so goddamned geeky. How was that his fault? His whole family had the same look – kind of pasty and challenged in the chin department. His family never had the money to dress cool, not that he would have known how to dress cool even if they did. His dad had a bunch of different jobs when Mike was growing up in Paducah. Dad worked in an office at a car dealership but lacked the charisma to sell the cars. Then he worked at a grocery store, but quit when he kept getting passed over for assistant manager. He was a mail carrier when he was diagnosed with colon cancer. Dad knew something was wrong when he couldn't get through his route anymore.

Jeopardy over, Mike surfs around and finds a Law and Order episode. He gets reassurance from the predictable formula of the show. He half-watches it, remembering the plot from previous viewings. Sharon hadn't liked Law and Order either. She said it was too New Yorky and she couldn't relate. Mike has always wanted to go to New York. He can't remember what he liked about Sharon, except that she was willing to go out with him. While Law and Order carries on its inevitable procedural path, Mike pushes Sharon from his mind by calling up notes on the upcoming holiday spectacular on his laptop. Unlike the fall festival, the holiday show is not a fundraiser. It costs more to put on than they make from donations. Mike figured out after his first attempt at a holiday show that you can't charge for tickets. Too many clients come from low-income families who won't come if they have to pay. There's nothing more depressing than doing a show with no audience.

Mike loves putting on these shows. He goes down the list of songs and skits that make up the program. No one realizes how hard it is to produce a show like this. About 30 clients participate, most of them willingly. Of those 30 clients, maybe three can be relied on to learn a few lines, recite them on cue, loudly enough to be heard beyond the edge of the stage. Of those

three, only one has what you might call stage presence. Over the last couple of years, as a result, the holiday spectacular has become The Anthony Show. Anthony is a big ham who demands a lot of attention, which can be annoying under normal circumstances. One day out of the year, it comes in very handy.

Anthony was the mascot for his high school's football team, which he never lets you forget. Not an official mascot, with a big-head costume. He was an equipment assistant, and the guys joked around with him. Once during a game that the team was losing by 35 points, they let Anthony run a play. A picture of the charitable moment ran in the local paper, and the team was applauded for their generosity of spirit. Mike is cynical about that. He thinks they were trying to go viral on Instagram. That didn't happen, but Anthony has been reliving his triumphant moment on the gridiron ever since. It reminds Mike of that song about the guy in the bar who can't let go of his glory days. It makes Mike sad that the moment will probably remain the greatest accomplishment of Anthony's life. Being disabled sucks. Mike never had anything like a glory day until he came to Upward Bound. Now he's had several of them.

Mike falls asleep on the couch with his computer on his stomach. The next morning, he puts on a clean shirt in honor of the first day of rehearsals. He always wears a tie to work, although the dress code at Upward Bound is casual in the extreme. You have to be ready for all kinds of messes and contingencies. But Mike likes the authority that a tie gives him. He makes the staff wear easily identifiable matching t-shirts to distinguish them from the clients. His tie distinguishes him from the staffers. He gets into his car, counting off the list of things that need to be fixed. His job makes it hard to get stuff like that done. He drives to work, feeling like he just left the office a minute ago.

When he gets to Upward Bound, Edith is in her wheelchair waiting for him to unlock the door. He has the only set of master keys. Another signifier of his authority. Edith has to take the bus to work, and she almost always gets there before he does. Every morning he thinks to himself that he should either give her a key to the front door or get to work 20 minutes earlier. Seeing Edith slumped over in her wheelchair in the morning chill makes him feel guilty. Then he reminds himself how lucky Edith is to have a real job, thanks to him.

"Good morning, Edith," he calls out in the cheeriest voice he can muster. "Sorry to keep you waiting."

"That's all right, Mike," she answers. "Bus schedule's fault, not yours."

Edith steers her power chair behind the receptionist's desk and sets about getting ready for the day. Mike isn't sure why Edith is in the chair. He's no doctor and he's never asked her. He takes privacy laws about disabilities very seriously. He forbids staffers from talking to clients or their families about diagnoses, and he shuts down conversations about them amongst themselves. Edith has a weak, puny voice that annoys him, and she can prattle on if you ask her an innocent question, like "How was your weekend?" So he tries to keep chitchat to a minimum. Despite Edith's physical challenges, she doesn't suck as a receptionist. She's probably in her 50's, although she could also be in her 40's. She looks drab and haggard, but she honestly enjoys everyone who walks past her desk. The desk is at chest level, but she is shrunken in her chair and can't see over it. Parents, grandparents and bus drivers go right up to the desk and look down to exchange a few words with her when they are dropping off or picking up clients. Mike tends to avoid doing this.

Delia enters soon after Mike has opened up. They are supposed to arrive at 8, prior to being open for clients at 8:30. Delia is usually five or ten minutes late. Mike doesn't like this but

she has little kids and he figures she's juggling a lot. She is very attractive and also very sweet. He doesn't feel that being stern with her would be productive. He follows Delia into her office and starts peppering her with questions and instructions before she's had a chance to put her coffee down or her purse away. She learned the hard way not to leave personal belongings where the clients could get at them.

"So today is the first day of rehearsals. Is the stage area cleared away? Have you printed up the rehearsal schedule for the parents?"

"Good morning, Mike. How are you doing this morning?"

Delia seems sweetly determined to observe niceties before responding to Mike's urgent concerns.

"I want to make sure that Anthony has his script for today. Could you print another copy in case he forgets his?"

"Sure, no problem."

"And get me the sign-in sheet by ten so I can make sure the clients I need will be here."

Mike is in his office working on staging when Walter's mom sticks her head in the door.

"Hey Mike, you got a minute?"

Mike likes Walter's mom, she's mostly pleasant and supportive. But she can overthink things. Walter doesn't speak and can't do much in the way of activities. Mike sometimes wishes his mom would just relax and accept reality. But no...

"I would really like Walter to participate in the holiday show. He never got to do that sort of thing when he was growing up. It always made me so mad that the schools didn't even try to include our kids. They were trying to make things look professional and forgot about the spirit of the thing."

Mike shakes his head and makes sympathetic clucking noises. Internally he's rolling his eyes. Have you met Walter, he feels like asking her. What do you think he can do? It always strikes Mike as weird that he has to have these awkward conversations with parents whose kids are adults. About a third of his clients live in group homes. None of those families bug him about stuff like this. The others still live at home, and there are definitely some helicopter parents among them. Mike says all the right things to Walter's mom, but wishes he didn't have to deal with it. He knows Walter well enough to know that he would rather spin around in circles in the corner of the room than be on stage singing "Jingle Bells." Not that Walter could sing "Jingle Bells" if he wanted to.

Walter's mom goes away satisfied. Mike sighs as he sits back down and tries to figure out where he can stick Walter where he'll be the least disruptive. It's not that the show needs to be perfect. But members of the Upward Bound board come to his Holiday Spectacular and he feels like he's judged by the result. Oh well, Walter's not the only one in the cast who presents a directorial challenge. Maybe it would help if he stuck some kind of prop in their hands.

Something that makes no noise but would be like a fiddle toy to ground them to their spot in the back. Mike wishes he knew more about autism. He got to be the director of Upward Bound without any background in special ed or psychology. He came up through administrative ranks. Now that he's in charge, it would be embarrassing to admit that he doesn't know much about the dominant disability of his clients. He's gotten pretty good at faking it, thanks to his powers of observation. But he spends most of his time in his office, which is as far from the clients as you can get.

Mike keeps glancing at his watch, anxious to start the rehearsal. When it is finally 3:00, he enters the rec room, raring to go. First thing he sees is Anthony pacing back and forth on the

edge of the stage muttering to himself as if he's memorizing a soliloquy from *Hamlet*. Then he looks around and sees only about 15 clients sitting around in folding chairs. There should be twice that. He notes wryly that Walter is among the missing. He sends Carlos out to round up the rest of the cast. Carlos is his most reliable staffer and he has a way with the clients. Mike depends heavily on Carlos, which he tries not to let on. He realizes that he should probably give Carlos a title befitting his function, but he worries that having an Assistant Director would dilute some of his authority. One by one, eight more clients meander in, reminded by Carlos where they were supposed to be. Mike is prickly, irked by the lack of urgency. Anthony is the only one who's come ready to work. He's actually several levels beyond ready, well into the realm of anxious dervish. Mike decides to begin while Carlos rouses the remaining stragglers, including Walter. Mike addresses his cast.

"Hi everybody. We have a great Holiday Spectacular planned for you this year."

"Yay!" yells Anthony.

"We will rehearse Mondays, Wednesdays, and Fridays at 3 until the show on December 15. Make sure that your families and caregivers know the schedule. I emailed them the information, make sure they got it. It's very important that everyone is present for every rehearsal."

"Especially me!" cried Anthony.

Anthony's enthusiasm is not matched by anyone else in the room.

"We're all important, Anthony. Everyone has a role to fill."

Anthony continues pacing across the stage self-importantly, but he stops interjecting.

"We're going to start with the opening scene, which includes the whole cast. It's set right here at Upward Bound, with everyone gathering for a holiday party. Art imitating life as they say."

Mike and Carlos place the clients around the stage according to Mike's chart. Easier said than done. Some can follow instructions and stay in place, but most are like jumpy cats that prowl and slink and leap. Mike starts to get frustrated, but he sees the zen-like patience of Carlos and is better able to swallow his irritation. They get the opening tableau more or less set up. Walter is in the very back with a few of the other nonspeakers. Walter can't make intelligible words, but he can produce a lot of noise. The poor guy is agitated and makes high-pitched siren sounds almost non-stop. Carlos tries to calm him but has no luck. Mike finally has Walter sit out the rehearsal with staffer Andy standing watch over him. Not only does Walter chew up precious rehearsal time, but his expulsion from the stage deflates the others. They don't get much done in that first rehearsal, but that's why Mike starts in October.

The rehearsals continue and a handful of skits take shape. Since most involve Anthony and a few others, Mike keeps the meetings small most days. He only calls the entire cast once more before Halloween. Mike is obligated to make a big splash for the Upward Bound Halloween party. A fair number of clients can't tolerate wearing costumes. No big surprise that Walter is among these. Others are in group homes where no one bothers to help the clients put a costume together. But there are enough clients who love Halloween that Mike puts his Holiday Spectacular aside for a few days so that he can throw a kick-ass party. He has his staffers put up the decorations, and Carlos is sent to Smart and Final for candy. Mike dusts off the rec room audio system and locates the CD burned by some long-gone staffer with Halloween hits like "Monster Mash" and "Thriller." Mike invested some years before in a first-class Dracula

costume, and he knows he cuts an impressive figure. The party looks great and goes pretty well. The Walters notwithstanding, some of the clients get into the spirit. Anthony busts out a special version of the Michael Jackson "Thriller" dance that is unintentionally hysterical. The party starts at 3:00 and is over at 5:00, when the short busses arrive to take clients to their group homes and the parents come for the others. Mike tells his staffers to come in early tomorrow morning to clean up and take down the decorations so they can restore the rehearsal space to its distraction-free state. Mike goes home, takes off his scary make-up, hangs up his Dracula costume in its protective garment bag and treats himself to a beer. He has a dream that night about Santa's beard catching on fire.

Now that the Halloween detour is over, Mike commits Upward Bound fully to the Holiday Spectacular. He has non-cast members make little craft items for props and decorations. He recruits staffer Andy, who plays the piano, to run through the songs with the whole cast. Mike chose the easiest Christmas songs to remember and to sing, like "Jingle Bells" and "We Wish You a Merry Christmas," but even these still sound ragged and pathetic after three weeks. Mike calls Andy in for a chat.

"So how do you think it's going?"

"Okay I guess."

"Are the clients learning the songs?"

"Oh, I'm pretty sure they know the songs."

"It didn't sound that way yesterday."

"Yeah well, like I told you, I'm no choir director. Makes sense when you figure that they have trouble talking, too."

"Maybe there's a video on YouTube or something that shows you how to teach singing to our population."

Andy doesn't respond right away. Mike thought it was a pretty good idea. Andy has a pained look on his face. A long pause follows.

"I'm doing my best, Mike. They're doing their best, too. This is their best. I think it's fine. It is what it is."

"We want our clients to have high expectations for themselves. We want them to strive for excellence. Your attitude is not going to cut it."

Mike can swear he sees Andy roll his eyes. Damn kid. What does he know about striving for excellence. Mike sits in the back of the rec room that afternoon to assess the damage. He notes with irritation that Walter is pacing up and down, not even trying to sing or pay attention to Andy's directions. Others, like Drew and Down Syndrome Isaac, are really going at it. They seem to want to get Andy's attention or approval. Andy is funny with the clients. That's fine, Mike thinks, but you have to have discipline before you can joke around. Anthony sits in front, closest to Andy. Suddenly, Anthony stands up.

"I don't need to be here. I'm going to go practice my speeches."

Mike sees that stardom has gone to Anthony's head. He follows Anthony out and stops him in the hall.

"Anthony, you have to set a good example for the others. They look up to you as the lead in the show."

"But Mike, it's so borrrring. I can sing "Jingle Bells" already."

Mike can hear the piano and a couple of tuneless voices coming from the rec room. There are fifteen clients in that rehearsal, but you'd never know it. His shoulders slump in defeat. He puts his arm around Anthony's shoulder.

"Come on, pal. Let's go work on your monologue."

The show starts to come together in its fashion. The skits featuring the verbal clients are okay. Mike cuts one group scene so he can concentrate on the other two. One opens the show and the other closes it. Mike watched the Charlie Brown Christmas special several times while he was writing the show. The final scene inspired him. He'd like to use a Bible passage in his show, but he knows he can't. This is an eclectic group to say the least, and Upward Bound receives some federal and state funding. Mike writes the final monologue himself, going through old Upward Bound brochures and donation solicitations for inspirational phrases. He pictures it in his mind. Anthony center stage in the Linus role. Maybe I can get him to hold a beach towel to reinforce the reference, he thinks. Andy as Schroeder at the piano. Emma is the closest thing to a pretty girl Upward Bound has right now, plus she stays where you put her, so she goes next to the piano in the Lucy position. The rest of the cast is scattered randomly around the stage. His clients' dancing isn't that different from the Peanuts' kids' nutty movements. It's brilliant, Mike thinks. By the final rehearsal, the reality isn't that far off from his imagination.

Mike can't neglect the audience in his plans. He had gotten a call in September from a committee lady for a fancy charity in town that puts on a debutante ball for the rich girls. They always have the debs do a service project to give back to the community that has given so much to them. The lady, whose name is literally Karen, loved Mike's idea that the debs could play hostess at the Holiday Spectacular. She excitedly took on the tasks of providing treats and ushers. Mike has a meeting with the girls, Karen and a few of the moms. There is so much

female energy in the conference room that Mike can hardly breathe. He is so fully immersed in the challenged world of Upward Bound that he has forgotten that there's a whole other world out there. A world where the girls are beautiful and wear nice clothes. Where girls are bubbly and articulate and enthusiastic and smell so nice. The moms are a little overbearing, but they are here to help, not to demand something unreasonable. Mike gives a little speech about his Holiday Spectacular and what he needs from them.

"Our clients come from all different kinds of homes and cultures. Most are economically disadvantaged but not all. Their disabilities are diverse, too. Most have autism and intellectual deficits. We also have clients with cerebral palsy and Down Syndrome. You don't have to be afraid of them. We will have plenty of staffers present to step in if someone gets too excited. You'll know the staffers by their purple t-shirts. This is a really big deal for our clients. They look forward to it all year. Having you girls here will make it even more special."

"We have arranged a cookie bake and will have about 20 girls to man the dessert tables," says Karen.

"We're going to wear super-funny ugly Christmas sweaters to, like, be in the spirit," squeals a blonde deb. The other girls cackle along. Mike would rather see the girls in pretty party dresses, but he hates to squelch their hilarity.

The dress rehearsal arrives. It's not really a dress rehearsal with costumes, as the clients are wearing street clothes in the show. Mike tells them that it's in keeping with the "Charlie Brown Christmas Show" theme, but there's no money for costumes in the budget. There's not actually a budget, per se. If the debs hadn't stepped up, there'd be no refreshments. Money is a constant irritation for Mike. He has so many ideas for events. He'd love to do a big Hollywood Nite with a red carpet and their TV actress benefactor. The clients would love that. But there's

no money to do it the right way. It's as much as he can do to meet salaries and keep the lights on.

He's going to place a couple of donations baskets around the room on show night. Maybe some

of the debs' moms will have a heart.

The rehearsal goes just okay. The clients are either a little hyper or totally checked out. Both are annoying. Mike wishes he could smush the two behavioral states together and lead a cast that was engaged and competent. He does his best to mask his frustration in front of the clients.

"Okay everybody. Get in place for the finale."

The staffers move the bodies into position. Emma is placed by the piano and Tom's wheelchair is pushed to the front. Mike knows that the wheelchair tugs at the heartstrings. Tom can be his Tiny Tim. Anthony waits off stage for his big entrance. Andy starts playing the piano. It's not the Peanuts jazz music, it sounds like that Mariah Carey Christmas song, but that's fine. The clients move around awkwardly when Mike yells at them to dance. Oh god, he thinks, tomorrow night they're just going to stand there unless someone prompts them to move. Mike despairs, until Anthony strides out on stage with gusto. He is on fire today. He delivers Mike's cobbled-together speech like it was the Gettysburg Address. Mike feels a swell of hope. You would never mistake Anthony for a real actor, but he's got a disabled brand of charisma that his high school football team must have responded to. Mike recalls the old theater adage about bad dress rehearsal means great opening night. Today's rehearsal was a mixed bag. The Walters in the cast were a mess as usual, but Anthony was a star. Tomorrow could go either way.

Mike drives home feeling better than usual. He picks up a Waba bowl with brown rice and vegetables instead of his usual burger and fries. After *Jeopardy* is over, he finds *Love*Actually on a movie channel. The romantic stuff makes him think of Sharon, but not in a bad

way. He thinks about calling her and inviting her to the show tomorrow. He's got her number up on his phone, but hesitates. It's so last minute. She didn't dig the scene before. He couldn't bear to see the look of distaste in her eyes on what could be a good night for him. He puts down the phone. He watches Liam Neeson and his little boy embracing at the airport. It's heartbreaking and uplifting at the same time. Maybe his show can be that, too.

In the morning, Mike dresses carefully in his sharpest button-down shirt and khakis. He chooses his most classy tie. He keeps his sport coat on its hanger so it doesn't wrinkle. He doesn't make coffee. He's sure he would spill if he did. He greets Edith at the door and doesn't have to fake his cheery greeting.

"I'm sorry I won't be able to stay tonight for the show," says Edith. "If I'm not checked in at the group home by six they give out a penalty."

"I know, Edith," says Mike. Edith's restrictions are consistent. "We will miss you. It's going to be a great show."

Mike pops into Delia's office repeatedly throughout the day. He double- and triple-checks the assignment sheet to make sure there are enough staffers to set up chairs and tables after lunch. He planned the show for 5:00 so no one will be going home before. He can feel the nervous energy coursing through the clients all day. Every time he hears a behavioral outburst from somebody, Mike cringes. He says little prayers and mantras, hoping that everyone holds it together tonight.

After lunch is cleared away and the kitchen is cleaned, Mike has Carlos supervise the setup of the rec room. He doesn't want to risk putting the clients through a rehearsal, but he keeps them busy with low-stress activities. Anthony struts around all day, the very picture of selfconfidence. Mike wishes he could bottle whatever gives him that. The debs start arriving at 4:00. They are laden with trays of cookies, table coverings and centerpieces. Everything looks newly purchased, a luxury. Karen bustles about, directing movement with the air of a general. Mike feels her authority as a challenge to his own. He forgets that when two men, dads or husbands who got off early from work, enter dragging a substantial Christmas tree. Karen beams at Mike, "Surprise!" Mike is surprised, and delighted. A tree that tall costs a fortune in Upward Bound dollars and Mike never would have spent the money. It really spruces up the room. The dads throw up a couple of strings of lights and the girls produce a bin of plastic ornaments from Target. In the time it took the Peanuts characters to turn Charlie Brown's spindly misfit branch into a beauty, the debs' tree lights up the rec room. Mike sees it as a good omen.

It's nearly showtime. Families and guests are arriving and sitting in the metal folding chairs. He sees Walter's mom and, presumably, Walter's dad. She looks nervous and he looks uncomfortable. Mike desperately wants to work the crowd and greet the board members, but he knows he needs to meet with his cast and give them a pre-curtain pep talk. He sees Karen chatting with the board chairman like they're old friends, so he figures they're in good hands. Mike makes his way backstage, which is an area of the rec room set off by the old accordion dividers. The cast is gathered, packed more tightly than autistic people usually like. One of the Upward Bound moms has supplied the cast with brightly colored scarves and damn if they don't look like costumes. Mike adopts a serious tone.

"Okay guys. And gals. This is what you've been working for all this time. This is your time to shine."

Mike looks around at the faces. Some are slack and checked out, some are hyper with darting eyes. Anthony, as usual, owns the place.

Mike says, "Don't worry if you forget where you're supposed to be. Carlos will be standing right over there—" Mike points to a spot just behind the accordion divider "—and he'll remind you. Just have fun, and let's show your families what Upward Bound is all about."

Mike goes to the back of the rec room behind the audience. He's too nervous to sit. Andy sits down at the piano and starts lightly playing "O Christmas Tree" while Anthony, Drew and Emma walk to center stage. Anthony begins to speak.

"Hi Drew, hi Emma. Christmas is coming and Upward Bound isn't ready for the holidays yet. Let's do something, let's put on a show."

Mike's gut clenches. Something is off. Anthony is saying the right lines, but his energy is weird. He's trying too hard to be funny. He's taken it up 1,000 notches from the way he's done it in rehearsal. After he's finished his first speech, the whole cast comes out and they sing "Jingle Bells." A couple of them keep looking over to Carlos for reassurance, but otherwise it's not terrible. Walter, who's so far in the back that you can barely see him, isn't singing, but he also isn't turning in circles or making strange noises. He can see the back of Walter's mom's head as she moves around, trying to get a glimpse of her son. The song ends and there are a couple of skits. Anthony continues to deteriorate. He keeps forgetting his lines, which he hasn't done in weeks. He calls out loudly to Carlos to cue him. He almost winks at the audience conspiratorially, like a Saturday Night Live performer who breaks character and starts cracking up. Only the audience isn't laughing with him. Mike feels bad for Anthony, but then he's not sure that Anthony realizes how badly it's going. Mike imagines that Anthony also failed to comprehend how the football team really felt about him. Anthony thought he was one of them, but he was more like a court jester. Mike didn't need to be there to know this. They had a football team at McCracken County High in Paducah, too.

It's awkward. It's uncomfortable. The friendly audience doesn't seem to mind as much as Mike does. Anthony basically throws out the script and improvises. Andy plays a few bars of Christmas songs to cover overlong silences. Mike is so busy with his frustration that he doesn't see at first what else is happening. Verbal clients like Drew join in the improvisational spirit and play along with Anthony's concoctions. It doesn't make a ton of sense, but there's more cooperation and interaction than in the rehearsed version. Suddenly the actors notice the big tree that the debs brought.

Anthony says, "Hey guys, a tree has magically appeared."

Drew replies, "It's a Christmas miracle. It's a Christmas miracle. It's a Christmas miracle."

The cast comes forward as one and steps off the low platform that transforms the rec room into a theater. They gather around the tree as if it were the most beautiful thing they'd ever seen. To be fair, beauty doesn't have a lot of competition in this place. The audience leans towards them and the tree. All except Walter. Walter has moved to the front of the platform, center stage. He stands like a statue, facing forward, away from where everyone else is looking. Mike follows his gaze and realizes that Walter is staring at his parents. And Mr. and Mrs. Walter are staring right back. Walter's mom can finally see her son.

The time for Anthony's climactic speech has arrived. Mike holds his breath. He has no reason to believe that Anthony will remember his lines or be able to regulate his energy level.

Anthony looks around at his peers and starts to speak.

"Hey you guys, somebody did this nice thing for us. Mike, was it you?"

Mike shakes his head.

"So maybe there is an angel who wanted to bring joy to us. Sometimes it seems like angels forget about us. But we are special and we got this nice tree. I wish it was Christmas every day."

Anthony looks around as if he doesn't have any idea what to say. Animal panic in his eyes. Thank god Andy picks it up. He launches into a loud, uptempo "We Wish You a Merry Christmas." It seems to wake the clients up and they make a valiant effort to sing. The ones who have the motor coordination to do so, anyway. Walter is still center stage and he starts swinging his arms around. It almost looks as if he's conducting a marching band, if you have low expectations about keeping in time. The clients get excited, aware that they made it to the end. Anthony jumps up and down. Others mimic him. The group looks just a little like a clip from *Peanuts* if you squint. The singing decreases as the movement increases. Perhaps encouraged by Walter's semi-conducting, the audience starts to sing along. Some of the debutantes stand up and dance around at their seats. Mike guesses that there are cheerleaders and glee club members among them. It's a happy mess. Mike is disappointed that all his plans went out the window, but at least it was not a disaster. Andy brings the song to a big finish and the audience cheers. Anthony jumps onto the platform and bows repeatedly, the star in his glory. He almost shoves Walter over as he claims the spotlight. Mrs. Walter is once again relegated to craning her head to catch a glimpse of her son in the chaos that passes for a curtain call.

The audience and the clients move towards one another, hugging and greeting. The debs move behind the tables with their Pinterest-inspired cookie displays. They take pictures of each other for their Insta stories, their sexy poses competing with their intentionally ugly sweaters.

Mike looks around for the board chairman, but first sees Mrs. Walter being talked at by Karen.

He joins them.

"Oh, hey Mike, congratulations. That was so fun. Don't you love what the girls have done? It's so special that they could have this experience. It is so good for them. It's so wonderful of them to do this, right?" gushes Karen.

Mike is annoyed by Karen's deb-centered response to all his hard work. He glances at the face of Walter's mother. She looks stricken, as if Karen's oblivious comments were piercing her soul. He looks at the two women and compares them. They're about the same age, probably similar socio-economically. Both are attractive in an early-50's way. But Karen is snappily dressed – hair, make-up and Botox helping along. Mrs. Walter looks tired and stressed, wearing jeans and a boxy jacket. She is staring at Karen, as if she can't believe that this woman and her hothouse girls are trying to make this evening about them. Mike has always acted supportively towards his clients' families. He assumed that, by the time they land as adults in his facility, that the parents have accepted the reality of their children's place in the world. One look at Walter's mom's face (what is her name?) and he suddenly realizes that the pain of exclusion never fully goes away. Walter's mom never got to see her kid on stage in elementary or high school. And this damn woman won't even let her have this much-belated night.

Mike says, "Yes, we appreciate the cookies and the tree." Turning to Mrs. Walter (he must get Delia to look up her name, Edith probably knows it), he says, "And how about our Walter? He was terrific tonight."

Karen turns away as Mrs. Walter rearranges her face. "Yes, I couldn't believe it. It's almost like he got the audience to join in at the end." Mike assures her that he did.

The crowd swarms around the cookie tables. The debs' flashy poise is dimmed when they are forced to interact up close with the clients. Anthony valiantly tries to chat a few up, but is unmoved by being shut down. Mike is pleased by the turnout. Mike has a few words with the

board chairman, a local real estate developer. The guy does this because it's good for his image, Mike knows, but he takes his role seriously.

"Great show tonight, Mike old boy," he says. "I bet you're going to hit us up for more money next year."

"Actually, Brian, I've been meaning to talk to you about..." Mike starts. He's been waiting weeks to make an informal pitch for more funding. Brian isn't looking at Mike.

"Sorry, gotta run. The wife doesn't like me out on school nights. We'll talk soon."

And he's gone.

Mike looks at the donation baskets set up around the room. Only a few bills here and there. Mike goes up to Karen, who is chatting with another deb mom.

"Would you mind asking a few of the girls to circulate the room with the donation baskets? Who could refuse those pretty faces?"

A slight look of distaste crosses Karen's face. Mike catches it but doesn't know if it's a money thing or he was being sexist. She gets past it either way, and the girls are soon wending their way through the clumps of families, flirting and cajoling. Good call, Mike congratulates himself. Mike sees Andy sitting with a few staffers, eating a pile of cute cookies.

"Andy, my man. You, sir, and your magic fingers saved the day."

"Thanks Mike. Couldn't let the thing go off the rails."

"How did you know you might need some extra music?"

"I had a feeling that Anthony might crack under pressure so I brought a Christmas cheat book," Andy says.

"Good thinking. Thanks for all your hard work."

Andy nods at Mike and goes back to his conversation. Mike looks around. People are starting to leave. He cleans up a few empty tables, hoping the staffers might pick up the hint and help. Karen goes around to the debs and gives some quiet orders. The girls fan out across the room and get to work. This motivates Andy and the other staffers. A few clients and their families pitch in. Mike looks at his funny community. Camaraderie can happen in the strangest places. He is suddenly exhausted and wants to teleport himself home. He calls Carlos over and hands him a ring of keys.

"Would you mind staying and locking up? I have a spare set at home for the morning."

Mike has to show Carlos which key is which because he's never let anyone else handle them. Mike walks to his car. Walter and his parents are right behind him.

"Goodnight, Mike," calls out Mrs. Walter.

Lisa, that's her name. Mike remembers now.

"Goodnight, folks. Walter, you're a star."

One day not long ago, Jorge showed up in obvious distress. He arrives every morning on a short bus, so there was no family member who could brief the staff on what might have precipitated this unusual level of agitation. In case you're curious, my mother never allowed them to transport me on the short bus, even though it's a funded service. She always said it was about keeping me safe, but I also think it was about maintaining dignity. The fact that "short bus" is used in the vernacular as synonymous with "retarded" is part of it. But it is also a great challenge to be stuck in a small space filled with autistic adults who are rocking, flapping, and vocalizing. Even if I am one of them. Most Upward Bound families took advantage of the bus.

No one could say why Jorge was upset that day. I noticed that he kept trying to get into the closet where they keep the toys. A lot of adults with autism like toys that you're used to seeing in a preschooler's toy chest. I am pretty subtle about it, but there might be a bin or three of Thomas the Tank Engine and his friends in my room at home. So I had an understanding of why Jorge was clawing at the locked closet door that morning. He was in a terrible mood for whatever reason, and he really needed some quality time with Mr. Potatohead.

Carlos saw Jorge struggling and came over to help. He knew Jorge well enough to understand his objective. There's a rule against opening the Pandora's box of the toy closet when it's not the scheduled activity, but Carlos could see that this was becoming an emergency. He pulled out his ring of keys, and the clinking sound alerted other inmates. An excited little crowd gathered around him. Carlos was trying to tell the others that he was just getting a Potatohead for

Jorge. But everybody had a comfort item in that closet. Carlos opened the door just a crack and the others started to push in with anxious arms. Jorge smelled a threat. Moving at the speed of light, he yanked the special spud off the shelf and was out the rec room door before Carlos could register it. Another short bus had arrived and the door to the outside was propped open for a wheelchair. As big as he was, Jorge slipped through the gauntlet and was down the sidewalk in a stealthy dash. I followed to see what would happen. I wanted to be a human breadcrumb for Carlos to follow. He was still extricating himself from the scrum of toy grabbers. Finally Carlos rushed past me into the street, but Jorge was already down the block.

Jorge didn't go far, he wasn't running away. He just needed some space and privacy to commune with Potatohead. He ran across the busy street to the little park. A passing police car had to slam on its brakes to avoid hitting Jorge. On the other side, he sat on a parking berm and held on tight to the toy. Carlos was on the other side of the road and watched as the police car turned around and faced Jorge in the park's parking lot. The police got out of their car and were asking questions of Jorge. Jorge was rocking back and forth, clutching the toy to his belly and emitting a disturbing shriek. Carlos was waiting for cars to pass before he could dash across to the park. He could see that the cops had their hands poised over their guns, and started yelling at the police to back off as he ran across the road. The cops were barking out orders at Jorge, which only escalated Jorge's behavior. Jorge suddenly lifted up his hands to cover his ears, Potatohead still tightly gripped. Only God knows why the younger cop panicked at this sight. What harm did he think Jorge was going to do with a plastic tuber? The cop drew his gun and fired. Carlos had just moved in to comfort Jorge. The bullet hit Carlos in the abdomen. Another bullet wound up in a play structure behind them.

Mike and other staffers were running toward the park. I noticed that Delia the secretary was running fastest, a weird look on her face. The cop who had fired stared blankly at his work, frozen in place. The cop who hadn't fired called for an ambulance. Carlos lay bleeding in the parking lot. A small pool of blood gathered beneath him. Jorge was flailing. He never stopped vocalizing as he stood and jumped and flapped his hands. Potatohead flew out of his grasp and fell somewhere behind him, unable to placate any longer.

Things moved quickly at that point. The ambulance arrived and took Carlos away. Delia hovered and wept, and they let her go with him in the ambulance. We later learned that he passed away en route to the hospital. Despite the Mike's assurances that Jorge was not a psycho, just autistic, the police took him on a 5150, a 72-hour psychiatric hold. If you ask me, the trigger-happy cop deserved a trip to the loony bin more than Jorge.

When my mom heard about the shooting, she rushed over to pick me up. She hustled me out of the building in the chaos, not even bothering to sign me out. My mom kept saying, "Never. You'll never have to go back there. I swear." When we got home, I retreated behind my noisy bank of video screens. *Toy Story 3* was on the biggest one. The scene in the dump's incinerator on repeat. My mom came in. The ominous music alarmed her. I made no indication that the day's events had disturbed me. She's not an idiot. She led me to our workroom and held up the letter board.

"Tell me," she said.

I pointed, "JORGE WHAT HAPPENS TO HIM"

"Honey, I don't know. I can call Mike tomorrow. But even if he knows, they probably won't let him say. Privacy rules and all that."

She called Upward Bound in the morning, but learned nothing. She went online. That may have been a mistake. Trolls and assholes placed the blame on Jorge, the reason that Carlos was in the line of fire. Freaks like Jorge shouldn't be allowed near our homes or in our parks.

People like Jorge should be shipped off to an institution where they can't bother the rest of us. Of course, the language they used on Twitter was not so civilized. I screamed at my screens all day.

We got through those first few days, but I'm not sure how. I was basically numb. It hadn't been so long since we lost my dad, so I wasn't ready for another blow. I stayed on my noisy screens and Mom sat at her sewing machine with *Top Chef* reruns playing bingily on the TV. It's tough when your heart is trying to block the past, the present and the future. At least one of those ought to be tolerable. A week after the event, Mom got an email from Upward Bound saying that there was to be a memorial service for Carlos the following Friday. I felt a great and unexpected relief from this news. I hadn't realized how unsettled I was, not just by the shooting, but also by the abrupt, unresolved way I had ended that brief, rotten chapter of my life. I am grateful to people like Darla, Andy, and Carlos for seeing me, and in hindsight I think I formed a few actual friendships. I found that I wanted to say goodbye to Drew and Emma and Tom. I wanted to say goodbye to Mike, even though... even though.

The memorial gave us a reason to wake up a little. I needed something to wear. I would have worn something of my dad's. His funeral-appropriate clothes were old and dusty, and they didn't fit. He was more of a sweatpants guy. I have a uniform that I'm comfortable with: basketball shorts, a Pixar t-shirt and crocs. No buttons, no zippers. No tags on anything. Tags feel like cactus next to my skin. I have been wearing this since I was in pre-school. I have one soft polo shirt that I can wear to a nice place, but I had to do better than that for Carlos. Mom had the black dress she had worn to Dad's funeral, so she was set. I actually wore the lonely polo

shirt for Dad's service, because there was only so much I could handle that day. Dad would have wanted me to be comfortable. But I wanted to show Carlos respect, and I wanted to look like an adult to bid farewell to Upward Bound.

Mom and I went to the mall. I like the mall, even though it's obviously overstimulating. The lights and people and the thrum of fluorescent electricity that undergirds the floors and stores give my brain a bright holiday. Of course, I am rarely required to deal with clothing purchases. 99% of my wardrobe is purchased online. But once every couple of years I have to try on and buy something fancy, something typical people wear without thinking about it. Mom has figured out how to do this in a way that limits my agony. This time, she was particularly mindful as to how far she could push me. We went into the least swanky department store and she sat me in a chair with my iPad and phone. My tolerance issues are coupled with my weird body to make finding a nice pair of well-fitting pants a virtual impossibility. Mom went to the sale rack and quickly came back with three pants possibilities. I tried them on, with Mom commandeering the hooks and zipper. The second pair worked pretty well, so we stopped there. She also pulled two sportscoats, but they were too expensive, even on the sale rack. She announced that one of Dad's jackets would be okay after all. We also managed to find a pair of pull-on shoes that were reasonably comfortable, although they were hardly crocs. Once these tasks were performed, we walked through the Lego store and ate Panda Express in the food court. By the time we got back to Mom's car, I was feeling okay again.

We woke up Friday morning and went through the motions of our usual routine.

Sometimes a routine can be a lifeline. The air in our house was filled with tension and waiting for the clock to tick down another minute. Finally it was time to get dressed. Lousy fine motor skills and a lack of experience with little shirt buttons meant that Mom had to help me dress. As

if I really was the child that Upward Bound treated me as. I don't like this adult neurotypical costume. We almost had a problem when Mom had to tie Dad's 20-year-old tie around my neck. She didn't know how. Dad did it for me before. We looked it up on YouTube. It almost made us late.

The memorial was held in a big Catholic church. I had only thought of Carlos as belonging to Upward Bound, so it was enlightening to see how many other moving parts his life had. He obviously came from a large Latino family. I spotted Delia, the secretary at Upward Bound, in the center of a group of aunties and cousins. It had never dawned on me before, but I suddenly realized that Carlos and Delia were brother and sister. What must that day in the parking lot have been like for her? I was glad she was in the ambulance at least, so someone was with him who loved him. I saw a diverse group of young people consoling each other. I imagined them to be Carlos' kayak friends. If only they knew how often I had daydreamed about being one of them.

Mom and I just sort of stood there. People are generally disinclined to approach me, especially people who are perplexed by my disability. I get it. It's awkward to talk to someone who can't talk back, who makes strange noises with their fingers in their ears. No eye contact. (Early therapists made a big deal about eye contact, as if, if I met this elusive goal, I would make friends and blend into typical society. As we nonspeakers like to say, contradiction intended, I can either look at you or listen to you. Choose one. Your face in motion is so bright, so stimulating, so loud and beautiful, that my senses are overwhelmed. I must look away to focus on what you're saying. Typical people always get this wrong.) So Mom and I are used to hovering on the periphery of a crowd. We could see Mike. He's tall. Mom tried getting his attention to say hello, but he seemed determined not to see us. As if my leaving at that terrible

time was a personal betrayal of him. Even though I never really liked Mike, his coldness hurt.

Mom and I cut our losses and went into the church.

I am a back-row sitter from way back. I don't like anyone sitting behind me, I feel like they're counting my tics. I like having a little distance between myself and the central action. It lessens the sensory assault of the film, the speaker, or the entertainer. Mom says that she's the opposite. She loves the front row for its immersive properties. One of the countless personal preferences she sacrifices for my sake. We take seats in the back pew of the immense church. I watch people come in, although it looks like I'm looking at a muted video on my iPad. Peripheral vision is my strongest visual channel. It's like a superpower that keeps others from knowing that you're spying on them. I witnessed the family enter in sad, angry clumps. Carlos was the victim of a wrongful police shooting, not because he was brown, but because they were aiming at the autistic guy and missed. There were so many layers of wrong here that my brain hurt. Carlos was the best thing about Upward Bound. He treated us with respect, like we were human beings, like our differences were not a choice. I could see in the way that family members looked at me and talked amongst themselves that a big portion of blame for Carlos' death was being levelled at Upward Bound and, by extension, clients like me. I thought about Jorge, but I didn't see him. Of course he's not here. I doubt he had any staff or family that could have brought him. His family might not even know what Carlos meant to Jorge. While I wished Jorge could be here, I could fully grasp that his presence would have caused distress for Carlos' family. The weight of the world's pain was making it hard for me to breathe.

A pipe organ began to play a hymn. I didn't recognize it, but I'd only been in a church a couple of times. My mom tried to take me to the children's program at a progressive church when I was little, but my wild behaviors were too much even for those well-intended liberal

ladies. Once a church rejects you, for whatever reason, it's hard to view Jesus as a source of salvation. So I don't know many hymns. I listened to the pounding, thunderous organ and I thought of how dissonant the bombast was in relation to Carlos. He was quiet and sweet and thoughtful, the opposite in every way from this bullying sound, intended apparently to coerce you by force into following Jesus. The organ stopped. Everyone stood up and sat down a few times. I wasn't interested in the words being said. I couldn't really understand them in the cavernous building. There was no casket in the front, as Mom had said there might be. Maybe the police still had his body. I have grown up with a healthy skepticism about institutions that have failed me. Education, conventional medicine, psychiatry, religion, Upward Bound. I'm not skeptical about police anymore. I am legitimately, realistically terrified that someday a trigger-happy officer will mistake my unusual behaviors for a threat to society and mow me down too.

There was a big, poster-sized picture of Carlos propped on an easel down front. It was an old picture, maybe even his high school graduation portrait. What was funny was that Carlos looked like an arrogant troublemaker in the picture. His hair was long and his chin pointed in the air. The priest in front was finally talking about Carlos instead of God. It sounded like the priest knew Carlos a long time and he was very sad. Apparently Carlos was a little wild when he was a kid. His dad had left their family and the mom had to work two jobs. Older sister Delia did her best to take care of him. Delia went to college and got the job at Upward Bound. When Carlos got into some real trouble after high school, Delia got Mike to hire him. No one thought it would work. I heard Mike in the crowd let out a little snort-laugh, as if to tell everyone, "Yeah, I was there, I turned Carlos around." Carlos did turn his life around, although I doubt that Mike had much to do with it. Carlos had found himself in Jorge and Drew and Emma and me. His calm

center was located in our dysregulated brains. Yin and yang. Carlos was happy with us. I don't know that the priest said all that, but it was what I was thinking while he spoke.

The organ thundered again and a group of family members led the way out. Women clutched each other while the men tried to look stoic. Mom and I waited to leave. I kept looking for familiar faces to pass, but Mike and Delia were it. That made sense, I guess. Most Upward Bound parents would be working, and group home caregivers don't take clients to something like this. I think it's something else too. The inmates of Upward Bound were not adequately capable of communicating how important Carlos was to them, to the people who could have facilitated getting them to the service. I felt like I was representing all of us. I thought I had wanted some sort of farewell or resolution, but maybe the fact that I am here and they are not is the point. I am able to call my own shots, or point at them anyway. That sets me apart. I can't belong to this club of silence, I refuse, but I can tell stories from behind the front lines.

There was a reception in the church hall, but we didn't stay long. Mom said something nice to Delia. She is always so sweet and calm in her office – a reason I should have guessed she and Carlos were related – that it was gutting to see her so sad. After Mom gave her a little sidehug, Delia looked right at me and said, "Carlos always liked you, Walter. He mentioned that he was curious about your typing. We're going to miss you." I was stunned. I felt special, the good kind of special.

Mom said, "What do you say, Walter?" This prompt usually means that I am supposed to say, "Thank you," so I did. Sometimes this comes out as "Happy Birthday" or "It's time to go," so I was glad I nailed it this time.

Mike was still avoiding us. I grabbed four sugar cookies before Mom stopped me. They didn't have Coke, which was disappointing. Coke can help any awkward situation. Just then I

saw Mike hovering over Mom's head at the dessert table. He looked down and his face showed surprise, as if he just now noticed that we were there. I wasn't buying it, of course. I think that he didn't know anyone else either, and that it was less awkward to talk to us than to keep ignoring us.

"Well," he said, "Fancy seeing you here."

Good thing I don't have good fine motor control or I would have been rolling my eyes.

Mom to the rescue yet again.

"Yes, Walter wanted to pay his respects."

"I wish that more of the Upward Bound folks could be here, but it's a workday and there are clients to care for." This was an unspoken jab at us. "I assume that Walter isn't coming back."

"No, he's been through a lot lately and we're going to take some time to figure things out."

"I have some paperwork for you to sign, and you should check the Lost and Found box."

"Okay, we'll come in this week and deal with that. What do you say, Walter?"

My mind raced to summon the correct script for the moment. "Thank you," was the best response I could come up with, but I'm not sure it was right.

I finally made it clear that it was time to go. Mom told me to turn my voice down as we moved to the exit as discreetly as possible. We got home and I quickly changed out of the restrictive clothes. Time took on a slow, unreal quality. Videos occupied my hours but not my mind. Mom was absentminded. She forgot how much reading out loud helped soothe my agitation. I went to great, noisy lengths to remind her.

We went to Upward Bound on Monday. My stomach clenched when we pulled up. I sat in the lobby with Edith while Mom dealt with the paperwork. Delia was still out, so Mike had to do the copying and whatnot. There was nothing of mine in the Lost and Found box. I knew that. When Mom was done, we walked into the rec room. It was snack time. I looked around the familiar room and faces. I smelled the smells. They were alien to me already. The atmosphere was like a convalescent hospital, as if the building was reverting to its original purpose. As if the forest was reclaiming the clearing after the cabin burnt down. I was finally able to focus on the faces huddled over the plastic tables. I saw Emma, her nice face frozen in neutral, her sharp eyes darting under dull lids. There was Drew, prattling on, repeating my birth date without mentioning my name. A girl staffer whose name I didn't know was helping Tom eat his snack, but she was distracted and wasn't really looking at him. I remembered Ann and it struck me now much Tom must miss her. At the end of the table, hunched over so far that you could hardly see his face, was Jorge. He wasn't eating, he wasn't really there. There was an empty seat across from him. I wanted to go sit there, but as usual my body refused to initiate the action. Mom saw the seat too and led me over to it. In my heart I told him all sorts of supportive words. I hope his heart heard them although I don't know. Only Carlos could have helped him. I sat there for a while. Andy gave me a little bowl of cheese puffs, generic. Mom chatted with staffers and also spent a few moments with Tom. She put her arm around Jorge and whispered something in his ear. He didn't look up at her, but his big body leaned just slightly towards her. For Jorge, that was a hug. Mom gestured for me to get up. We stood in front of the people I'd been spending my days with for months. Almost no one looked up at me, but I knew that they had no more control over their bodies than I did.

Mom nudged me, "What do you say, Walter?"

I've got a script for this, I got it off of a *Blue's Clues* episode and I am capable of summoning it at will:

"Goodbye everyone!" I called out in my best, upbeat Steve voice. I even incorporated a cheery wave.

The only client to say "bye" back was Drew, but he said it several times. Andy and the staffers called out good wishes. Nothing to do but leave. So we did.

That part of our lives was done, and there was no chapter outline for what happens after this.

The first few weeks we treated ourselves to a staycation. We did the things I enjoyed when I was younger. We went to the aquarium, the science museum, the mall, and the movies. We ran out of ideas, my list of preferred activities is short, so we picked out a Dickens novel – *Bleak House*, why not indulge – and Mom read out loud a couple hours a day. I did a jigsaw puzzle. I came upon Mom squinting at the computer.

"I think I can get paid for being your caregiver," she said.

Her internet search generated numerous interviews with social workers, home visits from officers of the court, and paperwork. At the end of it all, she was officially a Service Provider and I was receiving SSI. We did the math. This new support was about equal to what Mom had been making at the hospital job. Neither of us liked being dependent on public money, but we were probably what the system had in mind when they instituted such assistance. Mom looked at our situation. Dad had always done the bills. Mom told me that if we moved into a smaller place, we could probably get by. This was a hard pill to swallow. This was Dad's dream house. But he wouldn't want Mom working and me in day care just to stay here. We put the house on the market and it sold quickly. Our lives were subsumed with house hunting and a million moving

boxes. Mom had to be ruthless about getting rid of stuff. This meant tossing Dad's ridiculous collections of bobbleheads, mini helmets and VHS cassettes. She broke down just a couple of times, like when she put the dusty skateboard signed by Tony Hawk in the Donate pile. She had teased him a million times about the dubious value of this precious artifact. We bought a townhouse in a quiet area. We moved. The less said about that wretched day the better.

The need for a new routine was crushing my brain. My mother was made painfully aware of this by my loud, uncontrollable scripting.

"You wanna pack the box?"

"You wanna get on the truck?"

The moving truck was long gone. We had already unpacked the boxes and put everything away. I knew we were not going anywhere, that we were where we were supposed to be. I was mourning my old life patterns and repeating the impossible scripts gave me a perverse comfort. The problem for Mom was that I repeated those obsolete scripted phrases about 150,000 times a day in an anxious high-pitched voice.

Mostly to shut me up and to give our lives some order, Mom instituted a daily schedule of reading. We finished *Bleak House* and moved on to *War and Peace*. That may sound like a joke, but we had time and nothing better to do with it. To break up the monotony of the reading, Mom had me do a couple of 20-minute writing sessions per day.

"Write me something about your dad," she said. "It will be nice to have your memories so we can look back on them."

So I wrote reminiscences about how he made bad jokes, how loudly he talked on the phone, how I could do no wrong in his eyes. After that, I wrote some memories about Carlos, about his love of the outdoors and how cool he was to the clients at Upward Bound. I also wrote

about Jorge, imagining how it must have felt to be him on the day that Carlos was shot. I pondered how Jorge was doing without him. I even wrote a speculative bit about how Jorge and I were friends for real.

Suddenly Mom and I had a new routine that filled our days with work that might not be literally productive, but still felt meaningful. In the breaks between our sessions of reading and writing, Mom did chores or her craft projects. She enjoyed quilting. It took her out of her responsibilities, and it was all hers. She was currently working on a quilt made from Dad's favorite old sports team t-shirts. I vegged out on my video screens. I could see us going on like this.

We developed two possible future plans: for me to transfer to a university and finish a bachelor's degree, or just keep writing and see what happens. Either sounded good to me. I was in no hurry. The days took care of themselves. The only thing missing from our benign stasis was a guy poking his nudgy head in the door. Mom and I were not like Carlos and Jorge. We were not simply content without our third leg. I had always thought of us three as a unit. Now I am seeing that Mom and Dad were a unit before I ever came along. She is missing an entire half of herself. I can't fill that space, but I'm not going anywhere.

Yesterday I pulled a typical Walter. I made a mess in the bathroom and my efforts to clean it up were unsuccessful. Mom has a sharp nose and she moved in on the situation. She has been through this so many times over the years that she barely reacts. No judgment whatsoever. This time, though, she let out the smallest sigh. It suddenly dawned on me that with us being home together all the time, Mom doesn't get much of a break. I wondered if Upward Bound would let me come for one half-day per week. We could ask Mike. I would tell Mom that it's not for her. I would say that it would be good for me to be around other people, just for a few hours,

that there were some people that I missed. It would give me a chance to keep my eye on everyone, to report problems that may not be apparent to others. Whether I like it or not, I have, perhaps I will always have one foot in Upward Bound. Even if I return to school or write something that someone besides Mom would want to read, the people at Upward Bound are my peers, both client and staff. We dwell in a place that operates outside the everyday typical world.

They are my people and maybe someday I can tell our stories.

Backstory material that will be parsed out in the narrative:

\*\*\*\*\*Mike's dad passed away when Mike was 17. Mike finished high school while working part-time and trying to keep his mother in one piece. His mom had always had a drink or two every day, but after his dad died, it was more like three or four. Then five or six. Mike put off going to college to take care of her, but after a couple of years he realized that she was never going to get better. She had no interest in it. He decided he had better get on with his life and he enrolled at WKU. It was 150 miles from Paducah so he didn't get home much. When he saw his mom it just made him feel guilty and depressed. She passed away right before he graduated. He missed the funeral because of finals. He went back to Paducah one last time to clean out the trailer where she had been living. He hasn't ever been back. Mike spent a few years working in Louisville at different jobs, but the life he was living seemed too much like his father's, minus the wife and kid. At 30, Mike got so tired of the lonely deadendedness of his life that he did the bravest thing he had ever done. He picked up and moved to California.

Yes, he had a dream of working in Hollywood, but he wasn't a naïve, Kentucky bumpkin. He had read a lot of articles and even a few books about how to make it in film and/or television, but of course the reality was something else. He would have been happy doing any entry level job. He submitted a million resumes. Not a single call back. He got a job at a convenience store, but he started feeling like he may need a Plan B. He didn't know where to start. He came across a catalog for adult extension classes at a community college not far from his studio apartment. The entire selection seemed geared to someone like him. Someone who wasn't supposed to be in an unskilled, minimum-wage job, but was stuck and needed a leg up. He didn't want to do anything like data entry or medical transcribing. He was already too socially isolated. He saw a class in the catalog about working with nonprofit organizations. This was intriguing to Mike. Of course you wouldn't get rich working for nonprofits, but that had never mattered much to Mike. But he might be able to find a job where he helped somebody or made the world better. A job like that could give you pride and recognition, which is exactly what he sought in a Hollywood job.

Mike took the class, learned what they had to offer, and easily found a job at a family services agency. He found that his degree from Western Kentucky had value in this arena, where BAs were rare. He had the authority of a tallish white male, but retained the obsequiousness of his dweeby personality that allowed him to get along with the ladies in the office.