

Finalist, Non-Fiction

Fiddler Crabs, Mosquitoes, and the Dreaded Yellow Bus
By Heidi Johnson-Wright

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I was diagnosed at 9 years old with a severe form of juvenile rheumatoid arthritis, and the disease's rapid course left me with major orthopedic deformities. By ninth grade, I sometimes used a wheelchair for mobility. By junior year of high school, I'd had a half dozen surgeries, including having both of my hips replaced.

I attended my town's public high school. I couldn't have imagined myself in a "special school" in which all my classmates were droolers, spazzers or limpers, like me. After graduation, I wasn't going to live my life in some parallel "crips only" universe, so it only made sense to go to a regular school.

And there's the rub. I could never pass as non-disabled. Anyone observing me for more than 10 seconds could see that. Yet I didn't particularly like the idea of being lumped in with kids with disabilities. It didn't seem fair to me personally, plus it seemed like the perfect way for the establishment to keep gimps under its thumb.

It would take me years, though, to get to the heart of the matter, to understand why this subject made me squirm. I could not embrace my identity; I was a self-hating gimp. But I was about to embark on a journey that would change all that.

The summer after my junior year, I was accepted into a National Science Foundation program for gifted high school students to study marine biology for a month in coastal Virginia. Each of the roughly two dozen participants was in high school; each had a major disability.

The subject matter intrigued me. I've always loved the ocean and its creatures. But the longest I'd ever been away from home was five days at a nature school camp back in fifth grade. When I was 10, the JRA had yet to destroy my joint mobility, and I could bathe, dress and get around on my own.

This time, things were different. Now I needed considerable help with personal care. Other than hospital stays, I'd never had a care giver who wasn't a family member. I thought this was why I felt trepidation. I couldn't yet admit to myself that I was uncomfortable around a bunch of kids

with disabilities. My parents were supportive of me attending the program. Perhaps they knew I needed gimp immersion therapy. Or perhaps they just needed a break from me.

It was a sweltering July day when we arrived in Wallops Island. Staff greeted us warmly when we arrived, then gave us a grand tour of the site. It was no-frills yet functional. Our digs were old military base housing that had been retrofitted for wheelchair access. Classrooms and a mess hall were onsite, although we'd be doing a lot of learning in the field. There was one payphone for calls home. Housing for boys and girls was segregated, and the kids with severe mobility issues had the downstairs bedrooms. Besides the faculty, there was plenty of staff to serve as counselors and to provide help with personal care.

My parents seemed satisfied, deposited my gear in my new quarters, hugged me, then drove off. Even if I ended up hating it, there was no way I would tell them. Asking them to make the 1,000-mile plus round trip back to Virginia before the program ended seemed out of the question. I was here for the long haul, like it or not.

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There were four other girls in my housing unit. Each of us hailed from a different state and coped with a different disability. A girl losing her vision to retinitis pigmentosa, a girl with severe burns who'd lost part of her hand and a girl with cerebral palsy who walked with crutches took the upstairs bedroom. None of them needed assistance with personal care. My roommate in the downstairs bedroom was an older girl with severe cerebral palsy who used a wheelchair all the time.

Eileen, our "RA" and personal care attendant, was a young red-haired nurse who treated us with kindness and the gentle nurturing of an older sister. It was her job to make sure my roommate and I showered, dressed and groomed. She had to ensure all five of us were up and ready for class each day, and in bed at a respectable hour each night. When she wasn't playing house mom, Eileen went on field trips with us to help us apply sunscreen and insect repellent, as well as to maneuver kids in chairs through otherwise impassable marsh muck and sand dunes.

The first couple of days were a blur of new faces. The days were structured around dawn-to-dusk schedules with little free time. During the few moments I had for reflection, I felt profoundly

lonely and homesick, and wondered how I'd ever make it through the next month. But soon, I began to bond with the girls in my dorm. Many nights, we would stay up after official "lights out," gabbing about our schools and lives back home between squeals of laughter.

By the end of the first week, I was enthralled with the program. Since I'd always been a study nerd, the classroom portion of each day was right up my alley. The level of difficulty of the material kept my interest but didn't overwhelm. The program was designed to challenge a group of kids of different ages, backgrounds and disabilities without leaving anyone in the weeds.

We were expected to learn about marine biology but also about each other. The deaf kids -- who all seemed previously acquainted from Gallaudet -- comprised nearly half of the group and all spoke via American Sign Language. Every classroom lesson and field visit was taught in both conventional spoken English and ASL. Even the blind kids and kids with mobility issues were taught basic sign language so we could all converse as we collaborated on various assignments. I remember how fascinated I was the first time I saw a blind kid and deaf kid talk to each other: the deaf kid signing in the hand of the blind kid, and the blind kid signing back.

Trips to the field were an adventure in and of themselves. The blind kids and deaf kids could move around just fine, so they could travel to the marshes or shore in cars driven by the instructors. Those of us with gimpy legs were transported in an old yellow mini-bus that looked like nothing I'd ever seen before. It was so careworn, it looked as though it had been driven, packed with hippies, to Woodstock, Altamont and a zillion points in between, then pushed off a cliff at Big Sur. We boarded "the dreaded yellow bus," as we took to calling it, via a manual fold-down ramp that, once deployed, was so steep it required great effort to push a wheelchair up it. It had no seat belts or wheelchair tie-downs (did the National Science Foundation have no risk management staff?) and seemed to have the same caliber of suspension as the sub-Saharan Africa donkey carts I'd seen on National Geographic specials. Consequently, this made for an interesting experience when traveling along unpaved, pot-hole strewn roads in the boonies.

Many mornings, we'd arrive at a salt marsh or beach nearly drowsy from the heavy, humid air, the heat already oppressive. The mini-bus would lurch to a stop. The ramp would be unfolded, its hinges creaking with rust. It would hit the ground with a loud WUMP.

The salt water would have destroyed my regular manual wheelchair in a couple weeks. So here my mobility aid of choice was a rusty, old chair my dad had bought used for \$50. After studying its dents and broken spokes, I figured its previous occupant must have aspired to be the Evel Knievel of gimpdom (or perhaps of his trailer park.)

In the field, the blind kids had no curbs or walls to use as navigation landmarks. They had to be guided by staff or other kids who could both walk and see. Those of us who couldn't walk on the unstable marsh grass or sand had to be pushed in wheelchairs to where we'd be doing field work. These same unstable surfaces were also murder on chairs, which become immobile unless tilted backwards. I disliked being transported this way, like a crate of kumquats on a cargo dolly. I had to deeply recline backwards with my feet up in the air, feeling both helpless and stupid. More than once, my pusher slipped in marsh muck and fell backwards, with me landing ass over applecart on top of him.

I would arrive at our field work site, the sweat collecting in my lower back, only to discover we were short a couple students. Some of the deaf kids would grow restless with the slow pace of the wheelers and would wander off. Shouting at them proved fruitless, for obvious reasons. Someone would have to run over to them, tap their arms and implore them to join the group. For the next couple of hours, we would bear up under the bugs, heat and challenging terrain in order to expand our little minds on the finer points of marine ecosystems.

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My home state of Ohio has its share of mosquitoes and biting flies. Growing up, I'd worn garden-variety repellent, but only on the occasional summer evening when the bugs weren't satisfied with chewing up my mom. In Wallop's Island, I applied and re-applied it all day long, with one last application – on my skin and across the top of the sheets -- just before bed. Such measures were essential unless one enjoyed the red welts and intolerable itching caused by bites from hyper-aggressive mosquitoes, no-see ums and horse flies, as well as huge green-head flies. In fact, the rhythm and routine of each day was dictated by one's efforts to avoid being bitten.

Waking to the morning sun meant checking to see what critters had gotten inside overnight. First pee of the day often included swatting at mosquitos while on the toilet. The 8am two-minute walk to the mess hall was miserable without a spray of bug juice. Once inside, there was brief

solace with my scrambled eggs and corn fritters. I walked back as swiftly as my arthritic legs would take me to brush my teeth before class. Being sequestered inside a classroom until lunch brought a delicious respite from the flying, biting menace, but meant I'd be battling flies all afternoon in the middle of some marsh. Back at base, the flies subsided but the badass nighttime mosquitoes swarmed around any human being who dared remain outside.

The bugs were both a constant topic of conversation and cause for kvetching. Like hipsters debating the best way to mix a martini, we each had our own favorite "cocktail" of Deep Woods Off and Cutter's and personalized way to apply it. The sprays worked, just not perfectly and not for very long. And God help you if your skin got moistened from sea water or rain. The dampness attracted the little SOBs like frat boys to a wet T-shirt contest. I called home and griped to my parents, which prompted my dad to mail me a bottle of super-repellant that contained DEET, an ingredient not included in regular sprays. I soon discovered this was the only shit that truly worked and kept the nasties at bay. The only trouble was that DEET is also a solvent that can dissolve plastics and synthetic fabrics. It also takes off nail polish. But that summer, the smartness of my wardrobe and nails were a much lower priority than the condition of my skin and sanity. But my success was to become my undoing. When my classmates saw how little I swatted and cussed, they started asking questions. I soon had to beg for another DEET shipment that I offered at cost to the itchy and desperate.

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To the credit of those who ran the program, recreation was viewed with as much importance as formal learning. We went ocean fishing one afternoon during which we came away with little more than sunburn and a few sea robins but had a splendid time. Our whole motley group spent one entire Saturday poolside at the home of someone who kindly volunteered to host us. On another occasion, owners of a local seafood restaurant comped us with a tasty blue crab dinner. We were invited another evening to dine with a local chapter of the Opossums Club organization. Things went swimmingly until their grand poobah told one of the counselors that they were expecting "them kids" to provide the post-dinner entertainment, perhaps some sort of gimpy Gong Show during which the crips would attempt the old soft shoe, the deaf kids would sign the Gettysburg address and the blind would sing because, like Ronnie Milsap, they make up

for their lack of sight with dulcet voices. The counselors politely declined, thanked the hosts for dinner and we beat a hasty exit.

Some of my favorite moments outside of class were trips along the Eastern Shore, to the beaches of Assateague Island. The heat and sun were intense, but I'd forget all about it with the first whiff of tangy salt air. I would spend much of the afternoon on the sand talking with classmates and being soothed by the rumbles of the surf. Sometimes I would screw up my nerve and have someone park me – rusty old wheelchair and all – on the wet sand at the water's edge. With each crashing wave, I risked being cartwheeled by the rush of the water. It was like playing chicken with the Atlantic's tidal flow. I usually wussed out once I got good and soaked up to my waist and could feel the chair starting to be dragged out to sea.

The best moment of the day was my turn in the beach wheelchair, a contraption resembling a chaise lounge on ultra-wide tires with a push bar in back. With help from someone willing to provide thrust, I would fly over the sand like "Big Daddy" Don Garlits, exhilarated by the naked speed I so rarely got to experience. Once I had my fill of scaring sideways-running sand crabs back into their holes, it was time to launch. The beach wheelchair was not only a master of the sands but also the surf. Its wide pneumatic tires and lightweight materials allowed it to float in water. The chair's pusher and rider were cautioned not to venture out beyond the knee-deep shallows, so we'd wait until the chaperones on shore were distracted, then make a break for it. We'd be limited to depths that brought the water up to the pusher's chin. This still allowed us to go out pretty dang far. Here I'd float serenely, like Cleopatra on her royal barge, pushing all life's distractions from my mind for a few fleeting moments.

People coming together can do wonderful things. But there's something primitive imbedded in human beings that -- when in groups -- compels them to create hierarchies. Which inevitably leads to judgments about who is better than whom. Teenagers who can't hear or don't see well or struggle to walk are no different. They aren't gentle, guileless, inherently trustworthy beings in some arrested state of development as those who buy into stereotypes would think. They're just as prone to establishing pecking orders and indulging in mean-spirited teasing as anyone else.

By the end of the second week of the program, we'd all become acquainted with each other. Cliques had formed, the same groupings of kids repeatedly sitting together at mealtimes and in

transit to and from the marshes or beach. At times, the banter was like that of teenagers everywhere: debates about the best rock bands, anecdotes about goofy teachers, raunchy jokes. Then something changed. The boys' teasing of girls about being flat-chested turned nasty. Words like "retard" and "dumbass" flew back and forth. Ugly stereotypes about different regions of the country were used as verbal bludgeons. We all gave as good as we got, but the most frequent target of the bullying was Wendell.

Wendell looked like he'd stepped right out the Ozarks, which he had. But not the Ozarks of the summer of 1981, but rather that of the 1930s. I could easily picture his family living deep in a mountain hollow, in a shotgun shack with an outdoor privy. He wore Coke-bottle glasses to make up for his very limited vision, had a wacky, cartoon-character voice and clothes that looked like rummage sale rejects. He seemed to be utterly clueless about the typical social interactions of teenagers. He'd barely respond to someone's attempt to include him in the conversation one minute, then drone on far too long about some topic no one cared about the next. And Wendell's favorite topic of all was the soft rock band, Bread.

Wendell was sort of the unofficial historian of Bread. He knew everything about the band: how they got their start, which of their singles charted and when, who produced them and played session for them on their records. Did I mention that he collected their music? Wendell had the complete Bread catalog on cassette tapes that he carried around everywhere with him in a plastic case. That's right: he carried around Bread cassettes with him even when we were ankle-deep in the salt marshes with the fiddler crabs. He did this until one of the counselors finally took him aside and told him to leave the tapes back in the dorm.

It wasn't enough that Wendell dressed like a Depression-era carny and sounded like a Hanna-Barbera armadillo, he also had to be the de facto fan club president of a '70s wuss rock band that my sister outgrew by age 14. He might as well have had the words "kick me" tattooed on his back. It would have been much simpler for everyone involved.

It had been a particularly humid day in the field as we rode back to base in the yellow bus one late afternoon. The heat and the green-head flies made everyone short-tempered and irritable. The ride that had started in sweaty silence soon turned into a malicious free-for-all of insults and put-downs. As usual, Wendell was clobbered harder than most, but we all took some hits. I don't

recall which rotten remark became the tipping point, but I do remember one of my housemates – a cute blonde who walked with crutches – taking charge and saying that things had to change. Initially, there were a few nay-sayers, but by the time we arrived back home, we all agreed to meet in the main classroom after dinner. Everyone had finally had enough.

I don't recall the exact things that were said that night, though I do remember passionate pleas for kinder, gentler interaction, and even a few tears. We all agreed to a moratorium on making fun of each others' hometowns and accents. The boys agreed to curtail their remarks about girls' bodies and the girls agreed to stop their speculating out loud about the size and potency of each boy's manhood. Opinions were to be respected; diversity was to be welcomed. Good-natured teasing was fine and encouraged. If kidding escalated to insults, the perpetrator would be called out on the carpet. For the most part, everyone abided by the rules for the rest of the summer. To this day, I still marvel at the ability of a group of 16- and 17-year olds to work together and bring positive change.

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I am sitting on a boy's lap. He has his hands around my waist. I can feel his warm breath on my neck and the muscle and sinews of his thighs underneath me. We sit together in a single wheelchair. Another girl and boy sit next to us in another wheelchair.

We spent the day ocean fishing, and after returning to our digs to shower and change clothes, we are enjoying an evening in a social hall on the base. The boy and I sit near the edge of the dance floor. We watch couples, individuals, odd groupings of teenagers gyrating about. Some deaf, some blind, some struggling with mobility. Some of the kids who use chairs are flailing their arms, spinning their wheels in adapted dance moves. I feel a little embarrassed for them in their awkward attempts at teenage normalcy, the thing we all long for, compelled by the never-ceasing quest to fit in. But part of me envies them -- even in their awkwardness – because I have not yet found the personal courage to be so bold.

The jukebox is turned up as loud as it can go so the deaf kids can feel the bass. Mick Jagger's voice blasts out, and is unmistakably suggestive -- even when singing about being spurned: "She's so cold, she's so goddamn cold..." The boy holds me gently but tight, as if he fears I will suddenly jump up and run away. I have no intentions whatsoever of fleeing. I am savoring the

warmth of his body beside me, beneath me. There are moments when I feel like our two bodies are melting into one being. I feel both energized and languid at the same time.

The air smells of cigarette smoke, sweat, Cutter's mosquito repellent and pizza. Kids and counselors are talking, laughing, singing along with the next song as Eric Clapton's voice booms from the jukebox: "She don't lie, she don't lie, she don't lie/Cocaine." For a moment, I wonder if my 90 pounds on the boy's lap is hurting him, but he shows no signs of being uncomfortable, and I push the concern from my mind.

The marine science program is drawing to a close. In a few days, all of us will pack up our belongings, say tearful goodbyes, board planes and buses or stretch out in the back seats of parents' cars and head back to our lives in Ohio, South Dakota, Oregon, California and other far-flung locales. I wonder if I will ever see this boy again, the one on whose lap I am perched. He lives several states away, and neither of us can drive. I find him cute, bright and funny. He's a southern boy, a Johnny Reb and I'm Cleveland girl, a Midwesterner to my core. I secretly hope I'll have my first kiss with this boy, but that seems too good to even imagine: the kind of unforgettable, gloriously cinematic moment that just doesn't happen to me.

The homesickness and anxiety I felt briefly five weeks ago seems like it happened in a previous lifetime. Although I joined my compatriots in their ceaseless bitching about the bugs, hours of fieldwork in the fierce sun and the mediocre cafeteria food, I have also enjoyed the best summer of my young life. I have learned to be comfortable among other kids with disabilities and so have begun the journey towards feeling comfortable with myself. It will be a long journey, but it has begun.