Rethinking Disability: Value in Human Difference

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A drooping neckline illuminated a shimmering, pink rose hanging beneath her neck. Her long, light brown hair had been pulled back into an elegant fishtail braid. She stepped in front of me, draped in an ankle-length dress. Lacy had found me amongst dozens of sweaty, laughing dancers at a weekly dance held at Children’s Association for Maximum Potential (CAMP) summer camp for individuals with special needs. Blaring music echoed in our ears as I brought Lacy into our small dance circle. At first, she gave me a puzzled look, but then, unexpectedly, she pulled me into a firm ballroom dance hold and began to challenge my perception of music. Moving my clunky, dirt-covered sandals to her beat, I remembered Lacy is deaf. The dance brought Lacy and me closer. For a brief moment, our different worlds were one.

CAMP provides opportunities that ultimately bring together two populations. By spending a week with one another, people without disabilities and people with disabilities learn to communicate with and understand one another.

Today, almost 20 percent of Americans live with a form of disability¹. This population continues to change as cures are found, and accidents and disease produce disability.² These individuals, however, aren’t always seen out-and-about — not in movie theaters, nor in a park taking a stroll. Even as children, they are hidden away in special education classrooms. This segregation between people with disabilities and people without has had adverse effects.³ For instance, a 1991 public opinion poll revealed that the number one discomfort for individuals without disabilities was feeling embarrassed or awkward when talking with people with disabilities; many people without disabilities did not know how to interact.⁴

During summer 2011, I interned at CAMP. My goal was to understand how, despite our human differences, a culture of understanding could be replicated in schools, workplaces, and public areas. Experiences of people with disabilities are universal. Campers may have more visible forms of disability, but everyone, at some point, can grapple with disability. For instance, before I arrived at CAMP I had been struggling with the unexpected passing of my own father a few months prior. CAMP provided a place for my disability to be acknowledged without being treated differently. I learned to accept my disability.

Through portraits of four individuals, like Lacy, I explore CAMP’s unique culture. My perceived notions of “restrictions” of people with disabilities changed upon meeting Jim, a 38-year-old man with an intellectual disability. Don, a 26-year-old man with cerebral palsy,⁵ revealed faults in medicalizing disability. By forming a friendship with Hyde, an eight-year-old boy with Down syndrome,⁶ I learned how CAMP allows campers and counselors alike to reach their maximum potential. Sally, a 21-year-old woman with cerebral palsy, challenged me to find a different way to communicate. These four portraits provide a positive perspective on disability and speak to how a culture of understanding can be created by merging two different populations.

Children’s Association for Maximum Potential (CAMP)

Stars at CAMP are like no other. They shine bright, beckoning campers to Texas Hill Country⁷ for a weeklong adventure. CAMP’s first camper, back in 1979, was Matt, a young boy with a dream to ride a horse. Matt had been denied entrance into
matically many summer camps due to his severe kidney problems. His doctor along with several other physicians decided that no child should be excluded because of disability. That summer Matt rode a horse for the first time. CAMP’s philosophy of acceptance regardless of disability still continues 33 years later.

This summer, CAMP beckoned approximately 835 campers throughout nine, five-day overnight camping sessions. Campers range in age from five to 42; they are divided into “tribes” based on age group and gender. Volunteer medical personnel work in an equipped infirmary to ensure each camper remains healthy. Counselors, mostly college and high school students, form a one-to-one ratio with campers on most weeks. Counselors undergo training, which involves information about direct care of individuals with disabilities and dignified, enthusiastic interactions with campers. Together, counselors and campers participate in recreational activities during the day. Then, each evening, they partake in a night activity. Weeks start off with a campfire and end with a dance. During the course of seven days, a unique friendship forms between camper and counselor.

Misperceptions of Limitations

Thin streams of sunlight peered through covered windows into our cabin. Sterilizing, cold air swept into our cabin, making our hairs stand on end. The cabin quickly filled with bustling campers as they shuffled in with large suitcases and greeted their eager counselors. Jim, one of my campers for the week, rolled his suitcase to a bed, and began to unpack. His hair, lined with gray streaks, didn’t quite match his young, fervent smile. Turning away from me, Jim pulled a brief out of his suitcase. Glancing around our cabin to make sure he was not detected, he rapidly transferred his brief to a backpack. Jim is not like the majority of Americans, who learn to use a toilet by age three. He is seemingly limited in that aspect. However, this limitation does not necessarily deem him entirely “unsuccessful” in all aspects of his life. “Unsuccessful” is often a term associated with people with disabilities. This prejudice can restrict more than the disability itself.

After transferring the brief to his backpack, Jim pulled a large, rolled-up poster from his suitcase. His dark eyes lit up as he quickly unrolled it. He held it up for everyone in our cabin to see. “Look what I made for our cabin!” The poster contained intricate, well-drawn images of traditional CAMP activities. “Pawnee,” his tribe for the week, had been spelled out in large, bubble letters across the top. His perceived disability had not limited his artistic talent.

The Americans with Disabilities Act (ADA) ensures equal opportunities for individuals like Jim. Theoretically, Jim, a 38-year-old man with an intellectual disability, has access to the same educational and employment opportunities as his mainstream counterparts. However, he may not always be given these opportunities. According to the Surgeon General, negative stigma still remains one of the largest obstacles for people with disabilities, leading to discrimination. Society tends to underestimate their capabilities. For instance, special education teachers may choose to teach dishwashing, rather than academics. Some students may not be able to grasp certain academic concepts, but by deeming their entire class incapable, teachers may withhold other individuals with disabilities from opportunities for growth. Changing attitude and perception can help ensure individuals like Jim have opportunities to maximize their talents.

Discrimination can also present in providing unwanted help for individuals like Jim. Our perception is that people with disabilities are at a disadvantage relative to others; we attempt to rectify this by providing extra help. As a result, they cannot explore their capabilities. For instance, Jim may have required more time to learn drawing techniques, but if others had stepped in, he wouldn’t have realized his artistic ability. This perpetuates the stigma that individuals with disabilities are incapable and unsuccessful. After my father passed away, I struggled to overcome restrictions others had placed on me. Losing my father had given me a limitation: I had become withdrawn and less spirited. People around me attempted to rectify my situation by showering me with gifts and removing my responsibilities. Coping required support, but I did not want to become a pitiful, helpless child. Accepting my disability would mean reinventing it as part of my identity. If I wasn’t given the opportunity to explore my identity independently, I would not have gained the skills to cope. As with Jim, I needed room to learn.

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Outside CAMP’s walls, Jim lives in a group home and works at a local hamburger joint. His hobbies include competing in a dance team and practicing sign language. His life seems to be just as busy as my own life of studies and extracurricular activities. With only a difference: as a college student at a prestigious university, I am not questioned about whether I am capable of particular tasks. I am not hindered, but rather, given opportunities to pursue greater prospects. CAMP recognizes this capability in its campers and allows individuals like Jim to excel by providing activities and support through volunteers.

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Great Expectations

He ran past me and bolted towards a pen containing goats. “Hyde, don’t run! We walk at CAMP! Hyde! Hyde!” I ran after him, exasperated. Sharp rocks flew into my dirt-caked sandals as I sped past staring campers. I struggled to catch my breath in the static Texan heat, as droplets of sweat began to border my dark, shaggy hair. Smells of goat manure and hay slowly filled my lungs. Since meeting Hyde, an eight-year-old boy with Down Syndrome, the afternoon before, I had been frustratedly chasing after him, telling him to stop climbing atop structures, and blocking his attempts to take his fellow campers’ toys. I finally caught up with Hyde; he had immediately run to the trees, half-stripped of their leaves, to gather food for the goats.

Hyde’s parents had “forewarned” me about Hyde’s behavior.24 “He’ll probably have this place torn down by Tuesday. He doesn’t listen. It’s a pain.”25 I stared at his parents, unsure how to reply. As a counselor at CAMP, I wanted to believe that every individual – camper or volunteer – could reach his or her personal best. For Hyde, I wanted to help him exceed the expectations his parents had set for him.

I had not always felt this way about individuals with disabilities. I started working with individuals with disabilities during my first year at Brandeis. I joined the Big Siblings Program and was paired with a young girl with autism.26 I had low expectations, taking her inability to speak and keep eye contact as permanent. During my two hour visits each week27 I began to see her respond to book reading and pictures. Her mother and I encouraged her to ask for what she wanted using a picture booklet, and I would identify images she pointed out in her books. Today, she can sign a few words, respond to her picture schedule, and say select words such as “bye-bye.” I hoped to see Hyde change over our week together as she had.

Individuals with disabilities often have low expectations set for them. When Walter E. Fernald began his school for the “feebleminded,” he had decided that a great number of his students had no potential; they would never be “self-sufficient.”28 His purpose in creating such a school was not to create a community where individuals with disabilities could thrive, but rather to remove these individuals who would produce “degenerate children” and “perpetuate social problems.”29 But many of those placed in his school did have potential. Two psychologists, Skeels and Dye, placed individuals like Hyde into wards where they could receive constant and committed attention from caregivers. These caregivers pushed their students to exceed expectations, and eventually their residents learned how walk, talk, and play games; moreover, each child showed an increase in IQ, with “gains ranging as high as fifty-eight points.”30

Our prejudices and assumptions about what individuals with disabilities are able to accomplish can oftentimes hinder an individual from reaching his or her maximum potential. Like Skeels and Dye, CAMP doesn’t place a limit on what campers can accomplish. Rather, it fosters an environment in which campers can explore and learn through various activities. To accomplish this, they train volunteers to respect each camper’s
autonomy and encourage volunteers to be persistent in positive interactions with their campers through a “campers come first” policy.31 Using this policy, I worked through my week with Hyde.

“Hyde, are you ready to go feed the goats? They’re ready for their breakfast!” We began making our way to the goats after breakfast for one of the last times. This time, we walked beside each other. In my pocket, I carried a crumpled piece of paper with 20 large stars drawn with a brown crayon. Each star signified Hyde’s effort at good behavior. Prior to our star-reward system, I had tried taking away toys and enforcing time-outs. He didn’t respond well to either. As a coordinator for an after-school program for elementary-aged children, I decided a different, more positive approach could be more motivating for Hyde. He received a star for saying please, saying thank you, walking, and waiting patiently. Through this system, not only did Hyde clearly understand my expectations of him, he knew I believed he could meet those expectations. As we approached the goats’ pen, I handed him his crumpled star-recorder to turn in for his special prize, a horse ride on a secret trail.

Decreasing my expectations for this individual with special needs could be considered a form of “modern racism.”32 This lowering of expectations for a minority group, while it may seem to be “understanding,” limits individuals in that group and sends a message that they are inferior to their counterparts who are able to meet higher expectations.33 And Hyde seemed to enjoy meeting my challenges for him, which allowed our connection to grow stronger over the course of one week. Turning to me, he stated, “I want you to ride with me,” and reached for a white helmet to place on my head.

At the end of our week together, Hyde and I greeted his parents immediately before the awards ceremony. “So how was your week?” His parents asked grudgingly, seeming to expect a negative answer. Smiling, I gave a recap of our exciting days together.

Humanizing Don

“Should we try the fruit punch?” I asked. Don, a 26-year-old man with cerebral palsy, peered at me through tiny slits, trying to keep the harsh sun rays out. His lanky arms swung alongside his wheelchair. Glistening skin stretched over his bony knees, while braces enveloped his legs.34 His upper body was stiff, straightened by a steel Harrington rod.35 A sweat-stained T-shirt stretched over his broad shoulders, covering a slender torso. After spending a morning outside, campers and counselors were guzzling drinks down as quickly as possible. Don threw his head back, opening his mouth in a wide grin. Remnants of grape juice from breakfast still hugged his top teeth. Using a straw I placed a few fruit punch drops onto his tongue. “How is it today?” I asked. Don moved his tongue up and down, grinning once more.

Don was happy to take a break from his usual gastric feeding tube. A bout of pneumonia a year prior had left him eating and drinking by this method. An illness that had also brought on an onset of seizures deteriorated his ability to control his mouth movements. Understanding his speech had become difficult. Despite his medical challenges, Don enjoyed his time at CAMP. A few times a day, Don and I would try a new drink, oftentimes blended juices and occasionally, melted ice cream. Like an expert wine taster, Don savored each new flavor that came into his mouth.

His mother had told me about Don’s excitement for coming to CAMP. Tired of hospitals and doctors, he looked forward to having fun, again.36 I had been working at CAMP for several summers but what Don’s mom said made me wary of the challenge I was about to undertake. My job was to give every camper I met a wonderful camp experience. But to Don, CAMP needed to become a place where life would be more than “eating, pooping, and sleeping.”37 CAMP needed to be a place where we would focus on his personality rather than his medical condition.

Traditional clinical psychology (used as a paradigm for disability) often characterizes disability as biological or physical.38 Therefore, for individuals like Don, his experience has been reduced to repairing his physiological needs. But the psychological model doesn’t take into account Don’s broader social needs. This focus on disability, rather than “the individual,” stigmatizes those with disability; they are seen as “nonpersons, incapable of the same feelings, goals, and role responsibilities” as those without disabilities.39 America conducted mass polio vaccination campaigns using this paradigm until 1979, when polio transmission stopped.40 During one campaign, a girl, similar to

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Don, grinned as a photographer took her picture for a March of Dimes ad in St. Louis. Dressed in pink and frills, she received a kiss from the mayor and even appeared in a telethon, where she dropped her crutches for a few seconds before she fell to the floor. The much-anticipated advertisement finally came out. There were two pictures: one of a boy and a girl skipping hand in hand, and the other of the girl on her crutches. A caption under the picture of the boy and girl read “THIS” in large bold letters; under the girl’s picture the caption read “NOT THIS.” The girl had become her disability; there wasn’t a possibility she could be the girl skipping hand in hand with a boy. Likewise, those trained under the traditional clinical model may disregard Don’s desire to experience taste, only seeing his disability.

A pre-medical student, I continue to train under a traditional clinical model. In my classes, I learn about maladies, including cerebral palsy and its effect on the human body. When I first began training, I was focused on rectifying physical maladies. I only saw disability. I saw no legs. I saw a wheelchair. I saw a “retard.” I didn’t see that individuals with disabilities enjoyed participating in sports, attending functions, and finding love. My medical training lacks a basic element: to recognize these individuals as humans with needs similar to yours and mine. Until I began to form friendships with individuals like Don, I did not realize this element was missing.

Barriers of the clinical model continue to be broken at CAMP using a new emerging paradigm in which focus is placed on the individual and his or her surrounding society. This focus is achieved by bringing together those with disability and those without disability, not for a medical purpose, but for pursuit of new adventures and excitement. CAMP provides experiences apart from our “struggles and strangeness.”

Don’s tongue had become bright red, matching the fruit punch I held in a cup. We began brainstorming great-sounding juice blends for our next meal, as another counselor set up a movie projector. After he finished, we moved to a yellow mat placed on the ground. I sat behind Don, holding him up, so that we could begin watching the Disney film Aladdin. We relaxed into our positions. Don grinned as his legs stretched to fill the yellow mat, and we began to laugh as Genie worked his magic in the song “Friend like Me.” We were no longer a college student and a man with cerebral palsy. We were two people, having a good laugh together at a movie.

Fostering Communication
Drool slowly pooled onto a towel on Sally’s cotton shirt. Her face was half-hidden beneath short, auburn curls as her chin rested directly on her chest. Her deeply tanned skin and deep brown eyes, matching my own, contrasted her bright, plaid shorts and purple shirt. Her hands sat on her lap. Sally, a 21-year-old woman with cerebral palsy, was unable to speak and barely able to move. Around us, children with a variety of special needs and their counselors chattered, serving themselves southwest chicken and potatoes. Smells of the spiced chicken gently tickled my nostrils, teasing my hungry taste buds. But food would have to wait for now.

I began setting up Sally’s gastric feeding tube, filling it with water and connecting it to an entryway on her abdomen. I opened a can of formula and started pouring the thick, beige liquid into the tube peeking out from under her shirt. The formula slowly flowed through as Sally, turning her head from left to right, scrunched up her face in displeasure. Her arms, tense and straight down, flapped in brief episodes as she continued to eat.

My sore arm tensed as I held the tube up. “Sally, I heard you went to SeaWorld this summer!” I said, hoping to connect during our first meal together. No response. I lowered my head, discouraged. Her chin still rested on her chest, and her eyes remained on her lap. Would I be talking to myself for the entire week? How would I know what she needed, when she needed to be changed and when she was uncomfortable? And most importantly, how would I learn about Sally? With all my other campers, I had discovered their personalities, and I had shown them mine. With Sally, I wasn’t sure she understood me.

But we were at CAMP. Its diligent pursuit of happiness, focus on silliness, and philosophy of understanding somehow allows each camper-counselor relationship to grow strong throughout the course of only one week. And by teaching dignity to all volunteers and allowing these individuals to partake in activities they wouldn’t do elsewhere, CAMP fosters communication between two populations that oftentimes do not communicate at all.

The question of separation or integration has always been a dilemma for minority groups like individuals with disabilities. While separation allows individuals like Sally to thrive at her own pace through venues like special education classes, it simultaneously separates her from
mainstream society. CAMP attempts to solve this dilemma by providing an integrated setting, with individualized care. Individualized attention allows each counselor to learn how to communicate and connect with his or her campers to form friendships.

I continued to feed Sally through her feeding tube, continued speaking to her and hoping that a funny or memory-eliciting phrase would pique her interest. Upon mentioning the end-of-the-week dance, she slowly brought her head up and peered at me through large eyes.

The Pawnee women, the oldest tribe at CAMP at ages 21 to 23, were preparing for their end-of-the-week prom. Sally elegantly wore a floor-length dark purple dress. Tiny beads shimmered down the diagonal lining of her dress, flowing from large flowers at the top. Light pink eye shadow graced her eyelids, and a touch of red glowed on her cheeks. A diamond bow brought a few of her curls into a delicate “updo.” A potpourri of flowery shampoos and conditioners gradually filled our cabin. Excitedly chattering about men they would dance with that night, Sally and I joined her friends in the line in front of the door.

We approached the outdoor pavilion, where prom would be held that night. The sun, bright pink in the distance, had begun to disappear into the trees. Little white lights from the disco ball floated over the floor, frolicking with a multi-colored light show at the front of the pavilion. Pawnee men had crowded in, sporting their fancy suits and colorful ties. Sweat and body odor slowly replaced the air as campers and counselors twisted their bodies and swung their arms. Loudspeakers pounded with the latest hits, overpowering the excited voices of campers. My black tutu swished around, adding much-needed formality to my look, which featured feet strapped into brown, dirty sandals and my sweaty, untamed hair. I grabbed the sides of Sally’s wheelchair, driving her backward and ending with a spin. Although Sally had raised her head a few times during the week, she had yet to lift her head during prom. Her chin rested squarely on her chest, and her face, glimmering with makeup, remained hidden.

I had hoped that before the end of the night I would see Sally’s face. A slow, melodic country song faded away, as a loud beat began playing on the speakers. We started dancing crazily to the new upbeat song, thrashing our heads and bodies from side to side. CAMP wasn’t the place for discomfort. It was a place for fun, unhindered by human difference. Sally, picking up her head at her own pace, looked up at our unskilled dance moves. A smile slowly worked its way across her face, twinkling in the dim light. In that moment we spoke the same language.

Conclusion
Lacy changed my perception with a dance without music. Likewise, my campers taught me new lessons through their unique stories. While people may have disabilities, they are first and foremost people with desires and goals, people with talents, people who communicate—perhaps in a different manner, and people who can meet high expectations. Don, Jim, Sally, and Hyde shaped my perception of culture at CAMP. They challenged my preconceived notions and gave me insight into the value in human difference. More importantly, we became friends.

The Disability Rights Movement continues to grow as policies are created to accommodate participation restrictions. Policies have been created to subdue discrimination in the workplace, and special education classes work towards providing people with disabilities equal opportunities in education. However, many people are still reluctant to interact with people with disabilities, fearing the unfamiliar. This isolation makes people with disabilities a minority group that often is overlooked and stigmatized.

By integrating people with disabilities and those without in a fun manner, CAMP allows campers to become mainstream. However, this positive environment largely remains within the gates of CAMP. CAMP does not constitute the entire world. In our fast-paced American culture, people are oftentimes not willing to take time to learn about another person, and many don’t approach interactions with people with disabilities with a willingness to understand. Still, by dispelling common preconceived notions about people with disabilities among new counselors and staff each summer, CAMP culture can gradually be pushed to high schools, colleges, and workplaces. Organizations like CAMP have the potential to humanize and empower individuals with disabilities outside of CAMP. Perhaps through caring for and interacting with individuals with disabilities we, too, gain a sense of humanity.
Notes


8. Matt's doctor worked at an Air Force base. The doctors that accompanied her were also from the Air Force.

9. Associate CAMP Director, Recorded Lecture, 7 June. 2011.

10. CAMP Director, Informal Conversation, 12 Nov. 2011.

11. Tribes, from oldest to youngest are as follows: Pawnee, Mohawk, Apache, and Cherokee. These tribes are further divided into gender: Squaws are females and Braves are males. Campers participate in most activities with their respective tribes. Journal Observations, 23 May. 2011.

12. The exception to the one-to-one ratio is adult-only weeks. Journal Observations, 23 May 2011.


18. "Mainstream" refers to individuals without disabilities.


24. At the start of each week, counselors conduct an informal interview with the parents or guardians to obtain information about direct care, behavior, and special routines. Journal Observations, 29 May. 2011.


26. I began working with my mentee toward the end of my first year at Brandeis; she was 6 years old. I continue to work with her today as a senior.

27. As part of the Brandeis Big Siblings program, I am required to meet with Lena for at least 2-3 hours each week. Visits can include visits to festivals and museums, or doing activities such as coloring and reading.