

Chapter 1

# Growing Up

I have four children: two have a hearing loss, one is dyslexic, and two are gay. So, I have a diverse set of children. Your child is an ordinary kid who has some different challenges. Treat them that way. Let them fly.

—Stanley Lieberman (my dad) speaking to the parents of campers



Photo 2. Lauren at her high school graduation with her father Stanley, mother Janet, sister Ann, and brothers Marc and Eric.

## Dad, Can I Have a Unicycle?

My dad spoke affectionately but firmly. “If you don’t learn how to ride this, I am taking it back to the store.”

That was all the motivation I needed, after begging him for a chance to ride a unicycle. His best friend from the Air Force had recently visited with his three children, bringing two unicycles, and I had just begun to get the hang of it when they left. I begged my father for a unicycle until he relented, and then I was up at 6 a.m. each day practicing. For a while, I practiced nearly every available waking hour. My father never took it back to the store. To this day, I often ride my unicycle a mile and a half to the Brockport campus and back, and for the occasional birthday party for friends as “Happy The Clown.”

I grew up in the 1970s in East Goshen, Pennsylvania, on the western fringe of Philadelphia’s suburbs—surrounded by cows, corn, graveyards, and fields. In the Bible, the “land of Goshen” was the patch given by the pharaoh in the time of Joseph to the Hebrews, who farmed and raised livestock east of the Nile for more than 400 years until they decided to hightail it out of Egypt with Moses during the Exodus.

As a child, I seldom thought about Egypt or the Exodus. I was too busy playing sports. At home, sports equipment was littered everywhere: a tetherball in the backyard, a basketball hoop in the driveway, horseshoes on the lawn, pogo sticks in the garage, a Ping-Pong table in the basement. You could hardly walk around without tripping over archery bows, tennis rackets, and bikes.

I especially loved it when my brothers received Big Wheels—plastic tricycles that could sprint forward and then stop on a dime. We would ride them as fast as we could, then jam our feet hard against the pedals and spin out in a 360. Even better was the thrill of streaking down the small hill we lived on and spinning out at the bottom with our neighbors Johnny and Robby.

We played outside for hours every day after school. My competitive juices flowed early in life as I would try to break my own records: hits on the Ping-Pong table, foul shots in the hoop, or ringers in the horseshoe pit. When I didn’t have a piece of sports equipment in my hands, I would walk on my hands. To get the mail I’d walk upside-down through the garage and down the driveway to the mailbox. In school, I played every team sport I could—tennis, lacrosse, gymnastics, cross-country, and indoor track—and planned to go to college as a physical education major.

## Introduction to Adapting

Just as sports started early with me, so did adapting, although I never called it that. It was just normal family life. My older sister Ann had a beautiful head of brown curly hair and was way beyond her years in academics. She was also born hard of hearing. When she needed hearing aids, our parents spared no expense. In those days, hearing aids didn't work very well, so she had a hard time eliminating background sounds. We learned to face her when we spoke, and to avoid covering our mouths. It was my first lesson in lip reading.

My younger brothers, Marc, and Eric, were active, energetic, and fun little boys, always ready to play games outside. Marc had dark curly hair, sparkling eyes, and very long eyelashes. Eric's curly reddish-blond hair and huge dimples enhanced his adorable smile. What I was too young to notice was the delay in their development. Both were held back in first grade so they could catch up with their peers. Eric, the youngest, had oral motor problems. He often needed to be reminded to swallow. My parents were concerned about both boys, so they took them to a Doman-Delacato clinic in Philadelphia. Marc was diagnosed with dyslexia, which was not a common label, and difficult to treat in the 1970s. Both were given homework exercises involving patterning therapy. My mother sewed patches onto the knees of all their jeans, and every day the boys had to crawl, first moving one arm and then the opposite leg forward in what's known as reciprocal crawling. They crawled through the tentacles of our 1970s lime-green shag rug as if they were crawling through a field of grass. We'd call out "right, left, right" as they traced patterns around the large wooden dining table for fifteen minutes every day. Eventually the patches faded to white and the tentacles of the rug wore thin.

The training didn't end there. Using only their eyes and not their heads, they had to follow the beam of a flashlight for a set amount of time. We glued a penny to the middle of the flashlight for Eric so it would be easier for him to follow. For Marc, we used a penlight. He had to follow the pinpoint of light—up, down, left, right, up, down, left, right—for ten minutes at a time. These exercises helped to strengthen their eye muscles to make it easier for them to read.

The therapy became a family effort. I helped Eric with his lip strength by pinching his lips between my fingers using two hands. His job was to pull his lips apart to develop lip strength. It was a messy way to build lip strength, and not much fun for me as a child, but I was told it was

an indispensable exercise, so neither of us gave up. He was as invested in the exercises as we were. His dimples emerged each time his lips left my fingers—five, six, seven, giggle, breathe, wipe, start over.

Every day, Ann, the boys, and I had to come home half an hour before dinner to help our brothers with their exercises. My parents always rang us in from the neighborhood with a large bell, and when we started going in early, our friends asked us why. We told them we had extra chores. At nine years old I was a bit resentful about the imposition on my schedule, but deep down, I knew what I was doing would help my brothers. It was not a chore; it was a commitment to each other as a family that would ensure each of us would reach our full potential. That was the first time I recall feeling the satisfaction of caregiving and the commitment to reaching potential.

Marc is now a district judge in West Chester, Pennsylvania, and Eric a manager at the School of Professional Horticulture at the New York Botanical Garden in the Bronx. Ann has her doctorate and is a professor at West Chester University in Pennsylvania.

Meanwhile, I was experiencing my own challenge: a very short attention span. Today we would call it Attention Deficit Disorder (ADD), but in those days no diagnosis or prescription existed. To deal with the obvious but undefined condition, my mother invented a practical explanation. She told all of my teachers that, like Ann, I was a bit hard of hearing and therefore had to sit in the front of the classroom. It worked. Up front, I was much more attentive with fewer distractions. I innocently perpetuated this story about my hearing deficiency throughout my school career and told all my teachers I had to sit up front. In college I did the same, but when I took my adapted physical education classes, I realized I was not hard of hearing at all. I had inadvertently learned ways to cope with my ADD.

## Going to Camp

Another way Mom and Dad helped us reach our potential was ensuring that camps were a part of our childhood. I was seven when Mom started as nature director of a Jewish day camp. (One of the perks of having a mother on the staff was taking home some of the animals at night and on weekends!) After that, for four summers Mom was arts and crafts director at Camp Arrowhead, a position that enabled the four of us to go to camp for free. Camp Arrowhead had two trampolines flush to the ground so you

could safely jump as high as you wanted. The camp also had canoeing, fishing, tennis, volleyball, kickball, swimming, archery, horseback riding, nature study, theater, hiking, and a zip line down to the lake. Our daily schedule was any child's dream. In the morning we would have archery, trampoline, tennis, kickball, and swimming. After lunch it was volleyball, canoeing, arts and crafts, and nature study. The next day would be more sports and games all day.

At the time, my mother was working on her PhD. She could have taken a job for the summer and earned much-needed money, but instead she volunteered so we could attend camp for free. It was a powerful realization for me, later, how important our camp experience was to her.

Mom taught us all candle making, sand painting, string art, rock painting, gimp, paper mâché, hook rugs, and macramé. She also managed to bring home the leftover materials so we could do arts and crafts all year. To Mom, camp was more than playtime. It was learning, doing, and sharing, and she made a long-term commitment to make camp part of our lives year-round. One of the best parts was that Mom had the master key to every activity. The camp was only three miles from our home, so on the weekends we packed bags and went there for the day to use the trampolines, archery equipment, canoes, swimming pool, and even the zip line.

This passion for camp—I stayed on as a counselor at Camp Arrowhead even after my freshman year in college—would transform my future in ways I couldn't imagine as a child. The new friends, the sports accomplishments, and the feeling you get from spending that time together were all things I strove to replicate when I started Camp Abilities.

## Choosing a Path in Higher Education

I am glad that any assessment of my life doesn't use my high school years as the grading period. I was not what you would call an overachiever. I skipped classes sometimes and seldom studied. What's more, as student council president, I could infect some of my classmates with my lack of focus by writing them passes to work on fundraisers or school events, which in fact enabled them to get out of class and play wall ball in our three-walled senior courtyard.

I doubt any adult ever called me an academic role model in high school. I did receive praise for student council and my extensive involvement

in sports. That I was voted “most extroverted” by my classmates may indicate how my socialization skills covered up for my lack of academic effort.

College loomed, and I wanted to go to Penn State’s main campus in the town of State College. I didn’t make it. The university said I could go to the Hazleton Campus for two years and then re-apply. I was devastated. If I were to attend Penn State, I wanted only the main campus. But I had a plan B. My sister Ann was a student at nearby West Chester University. I decided to enroll as a business major—not that I felt any passion for a business career, but I wasn’t sure my family would approve of a physical education major. I got lucky and landed in the honors program, despite my less-than-stellar high school academic record. My academically gifted sister, Ann, was already in the honors program and doing very well. I suspect my mom made the case to the director that if Ann could do it, Lauren could as well.

West Chester ended up being the perfect place for me. I moved into the honors dorm with something of a “What-am-I-doing-here” feeling, but the classes turned out to be well suited to my learning style. They were set up as seminars with discussions, papers, and sharing of our feelings and opinions—good for the extrovert in me. Excelling in these classes boosted my academic confidence more than I ever thought possible. I then changed my major to physical education because I knew this was what I truly wanted to do with my life.

Early in my freshman year, as I was hurrying down the stairs on my way out of the South Campus complex, a sprawling maze of courts, pools, and other physical education facilities, a dark-haired woman in a silky blue sports jacket caught my attention. I recognized this professor right away; my friends on the tennis team talked about her often when they spoke about classes that they liked. Monica Lepore was the professor of adapted physical education (APE) at West Chester University and a leader in the field of adapted aquatics. Outgoing and gregarious, she approached me to say hello.

“Hi, my name is Monica Lepore. Who are you?”

I introduced myself and smiled. “I would say nice to meet you, but I feel like I already know you, Ms. Lepore.” (She would soon be Dr. Lepore, after completing her dissertation.)

“Oh, yeah?” she smiled back. “Same here. Your friends told me about you and your interest in students with disabilities. I had a feeling we should get to know each other, Lauren Lieberman.”

“Well, now it’s official.” I shook her hand.

“It is.” She gave my hand a firm pump. “Let me know if you need anything.” Off she went, a blue blaze across campus. Little did I know, watching her sprint across the lawn, that this was the start of a lifelong friendship.

The first class I took with Monica Lepore was an introduction to adapted physical education (APE). As the name suggests, this is physical education modified so that people with disabilities can participate together with those who do not. For example, with only a few modifications to the program, a child with spina bifida in a wheelchair can participate with peers in a wide variety of activities. I learned in this class that the primary obstacle is seldom the child’s potential. It’s usually the unwillingness or lack of knowledge of those in charge to adapt a program so everyone can reach their potential.

I loved the class—and earned an A+. But I had somehow missed the fact that I could begin a concentration—that is, a specific area of study within the PE major, like a minor—in adapted physical education. And so, sophomore year, I found myself heading to the first session of a standard three-credit course on racket sports taught by my tennis coach. It would be an easy A for me. But Monica stopped me in the hall.

“Lauren,” she said, gesturing toward her classroom, “you should take this class instead. We need one more person to meet the minimum number.” I glanced down the hall and saw a group of tennis team members standing outside the gym, smiling, and waving at me to join them. I turned back to Monica and asked what the class was.

“Physiology of Disability,” she answered. “You should take it. You did great at APE.” I peered into the classroom and saw friends from my major smiling back. I paused, conflicted. If I chose the Physiology of Disability class, it meant a lot of genetics, physiology, complicated medical terms, and anatomy—all for only two credits. The alternative was three piece-of-cake credits in racket sports. In a flash of insight, I saw which course would teach me what I needed to truly make a difference. My choosing the Physiology of Disability course was a turning point in my life. It was my entry into the adapted physical education concentration, an early step in the incredible journey to Camp Abilities, and the best decision I ever made.

Adapted physical education at West Chester was a rich experience, with rigorous and practical courses, an inspiring array of speakers, and opportunities for learning beyond the classroom. In March of my junior year, West Chester hosted the regional basketball Special Olympics, and Monica

asked if I wanted to volunteer. Of course, I said yes. The volunteers met for two weeks prior to the event to organize the teams and schedule the events, which would take place in the large physical education complex at West Chester. With six gyms, a pool, classrooms, and offices, the complex had multiple entrances and parking lots and could be tough to navigate. I was familiar enough with the buildings, but I had never helped with Special Olympics or taught a child who was intellectually disabled. My inexperience would surface quickly.

On the afternoon of the athletes' arrival, Monica and I waited at the registration table with a few other volunteers. The teams were supposed to sign in by 6 p.m. so they would have time to practice before the tournament the next day. A good while after six, we started to get worried. "Hey, Lauren," Monica said, "can you please look in the gyms to see if any of the teams are here? Maybe we missed them."

I went to the gyms and saw athletes in smart uniforms making basketball moves I couldn't dream of making—and I was a pretty good player. They dribbled expertly, sank lay-ups, and even dunked. I figured these were West Chester intramural teams. No way were they Special Olympians.

I went back and gave Monica the news: the teams were not there yet. So, we sat at the table for another half an hour, until Monica got worried and went to the gyms herself. There she discovered all the teams warming up as scheduled—they had simply come in through one of the many other doors in the complex. All those players I had witnessed making amazing moves on the courts were, indeed, Special Olympians. What a lesson that was. I had somehow equated "intellectual disability" with a general "lesser than." I had to flip my thinking to see them as athletes who just happened to have an intellectual disability. I also learned how a temporary embarrassment could lead to a fundamental change in attitude, something I was certain I would go through many times in my life.

That March weekend, I began to appreciate that to really master this field I needed to get involved in more activities outside of the classroom. I needed to shed my stereotypes of people with any disability—biases I didn't even know I had. In short, I needed to experience their world firsthand. Guiding cross-country skiers who were visually impaired in the Ski for Light program and coaching outdoor enthusiasts with visual impairment through the VIP program turned out to be essential early experiences in confronting my stereotypes and assumptions and beginning to recognize just how much people with disabilities are capable of.



I eventually graduated from West Chester University cum laude, having learned that focused hard work can produce results. What's more, I began to believe that if I could exceed my own expectations, so too could others. It's idealistic to think that potential has no limits, but it's realistic to believe that potential can stretch far beyond what we expect. A new dose of confidence moved me forward.

## More to Learn

I didn't feel ready to teach yet. I still had much to learn. So, I accepted a graduate assistantship at the University of Wisconsin at La Crosse—the alma mater of my professor and now friend Monica Lepore. In the yearlong program, I would gain a master's degree in adapted physical education, and more real-world experience working with people with disabilities. When it came time for the two-day car trip to La Crosse, it was Monica who joined me to help with driving. I could hardly imagine a better transition from my years at West Chester to new adventures at my beloved professor's old stomping grounds.

My year at La Crosse was an academically intense year of classes, practicums, internships, and research, but the variety and discipline were just what I needed. I learned sign language and supervised undergraduates teaching children with visual impairments and multiple disabilities. On Saturday mornings we hosted children with disabilities from La Crosse. For two hours, our undergraduate students taught them skills in the gym and swimming in the pool. The graduate students supervised the program and videotaped everything. During the week, we watched the videos and gave the undergraduate students feedback. Though the program started at 9 a.m. on Saturdays, we had to arrive at 7:30, which was not always easy given our full schedules throughout the week.

Learning continued outside the classroom. Bob Norby, one of my professors at West Chester, had moved to Winona State University in Minnesota and was coordinating the summer version of Ski for Light, called Sports for Health, a tandem-biking program for adults who are visually impaired. Tandem bikes have two seats—one in front for a sighted rider and one in back for a rider with visual impairment. One June weekend, eleven pairs of riders set forth from the Winona State University campus—and I was among them. We rode thirty to forty miles each day, making camp at night

near the Mississippi or St. Croix Rivers. The adults who were blind or visually impaired were accustomed to being independent at home and in their jobs, and they expected to move independently around camp as well. This meant everyone had to learn the layout of each new place we stopped for the night, including where the toilets were and where the gear was stored. It seemed easy to me, but I hadn't yet learned the challenges different places and situations could pose for people who are visually impaired. For example, if sighted volunteers didn't put bikes back exactly where they had been when we stopped, the participants who were blind would trip over them—which was extremely frustrating, as they had memorized carefully where everything was.

The disorientation caused by the carelessness of others was especially annoying for one independent gentleman who was unaccustomed to being guided all day. He refused to allow the mistakes of others force him into an unwanted dependence. After tripping over a misplaced bike yet another time, he decided to take a break and relieve himself in the nearby woods. Independently, of course. Unfortunately, discombobulated and annoyed after stumbling over the bike, he miscalculated the distance to his target toilet and stopped short of the woods, out in the open just on the edge of a field. Thus, while relieving himself, he also exposed himself. This served as an unmistakable cue to the rest of us to park the bikes and equipment more carefully.

Shortly after this lesson, I received another lesson about inventiveness from Martin, who was about seventy years old and totally blind. He was a whiz at setting up his tent each night because he had sewn Xs and Os along the seams to guide him in placing the poles. Martin could raise his tent faster than I could. He was also the inventor of the portable bowling rail, which enabled people who are blind to bowl independently. The rails aligned with the center of the pins to guide the bowlers' approach to the release point at the foul line.

These two men, both determined to be independent, reinforced my growing desire to help others do the same. At my graduation from UWL in 1988, I was beginning to see the link between my passion for sports and the importance of my education.

As I began to consider jobs, I tried to decide whether I wanted to work at a school for the blind or at a school for the deaf; really, I wanted to teach children in both areas. When I applied to the Perkins School for the Blind in Watertown, Massachusetts, I didn't even know about the deafblind

program—teaching children who are both deaf and blind. It was my sister Ann, the historian, who told me. “Lauren, that was the first school for the blind in the United States! *Helen Keller went to school there!*” As a child, I had read about Helen Keller, and of course I knew that she had changed the narrative of people who are deafblind in America; but I hadn’t realized that Keller had attended Perkins School for the Blind.

I was sold—Perkins was the school for me.