

The Handicap That Had No Name

By Ms. Dale S. Brown

My first memory of school is sitting on a hard seat, holding my muscles rigid, trying to concentrate on the teacher's words. "Is this all school is," I think, "just sitting?" I raise my hand.

The teacher calls on me and I stand up. "I'm tired of just sitting here," I tell her.

"Well, Dale, we're big girls now. We sit and we listen."

I sit. I squirm. Soon my seat is slick with sweat and my dress clings damply.

The elastic of my underpants cuts. I struggle but I cannot stay still; my body kicks and rocks.

"Dale, please pay attention!" says the teacher.

"You pay money, not attention!" I reply.

The class bursts out laughing.

"You weren't listening," the teacher says. "Now open that book on your desk to page one and mark all the triangles."

I complete the assignment easily.

"Recess time!" calls out our teacher. "Row one may leave."

I jump up happily and follow other children to the cloakroom. It is dark in there. I cannot remember which is my coat. I wait until everyone goes out and take the coat that is left.

The playground is a blacktop area. All the other children talk to each other, play jump rope, chase one another, and swing, but I do not know what to do or how to fit in.

I cannot do anything during gym either. I try and try to bounce a ball but I drop it each time and it takes off halfway across the room. I stare at the other children, effortlessly bouncing their balls. Up and down. Up and down. How do they do it?

"Can't you even try?" the gym teacher yells.

We practice tumbling. I squat but cannot figure out what to do with my hands to make my body roll. The gym teacher grabs my leg and throws me over. It hurts and I do not like the way the world whirls afterwards. The next time he reaches for my leg I kick him. Both he and my teacher are furious. They make me stand in a corner for the rest of the class. I am happier there.

In my recollections, school was a constant struggle that started upon awakening: to find my clothes, to straighten out the dress I tangled, to get my socks on properly, to identify the right shoe for each foot, and to tie the laces. Even managing my body was a struggle. It was hard for me to use my right arm and leg. My head felt heavy and hung down. I shuffled rather than walked and I leaned forward slightly. To move in a straight line, I often walked with one foot on the sidewalk and the other on the grass, or I kept one hand on a wall. When people told me to pick up my feet, I kicked each one up and then stepped down; I could not understand the difference between their way of walking and mine. I always spoke at the top of my lungs because I could not hear myself and "loud" and "soft" had no meaning. Sometimes I smiled with only one side of my mouth. I never blinked and my eyes were often crossed. They wandered randomly, which made it difficult for me to see.

I saw double until the second grade, when I had surgery. Afterwards, my eyes did not work well as a team, causing figure-ground and depth-perception problems. My eyes tracked improperly and it took me a long time to learn to discriminate visually and to focus.

My peers would snap their fingers in front of my eyes and laugh when I did not blink. They held fingers before me and asked, "How many?" I would guess the right answer and think they were trying to help me to learn better. They said I had more "cooties" (germs that could be passed by touching) than everyone combined. One child would touch me and then quickly touch someone else, yelling, "Dale's cooties! I quit!" That child would try to pass along my cooties, too. When we waited at the bus stop, they stood in a circle and I had to stand outside. One boy threw stones at me every day on the way home from the bus.

Luckily, I had one friend, Carol. We played together constantly. Through watching my peers imitate my movements, I learned what I was doing wrong.

I started trying to stand up straight with my shoulders back and my head up.

I learned to lift my knees when I walked. I liked holding my head up because

I could see the world; before, all I had seen was the sidewalk and my feet.

In the fourth grade, Mrs. Johnson was my teacher. She had art class every day and she tacked my pictures on the bulletin board. She also taught creative writing and loved everything I wrote. She helped me to put my poems in a beautiful book bound with red construction paper. Because she let me walk out of class when I became especially restless, I learned to sit still.

She gave us very little homework, so I had time to play. I used to practice throwing a ball against the side of the house and catching it. At first, I spent most of the time chasing the ball but soon I was catching it after one bounce.

In the fifth grade, our teacher was Ms. Rhiner. She had red hair and she liked me. But the homework started again. It took me an hour to write a paragraph; often I worked from the time I came home until it was time for bed. I wrote my work letter by letter. I got up from my chair only to get drinks of water. One night, I took a walk instead of doing homework. How I loved the cool evening air! But I felt guilty about that walk for weeks.

I strove to learn. I understood mathematical concepts, but my answers were often wrong. "Careless errors," I was told. Yet no matter how carefully I checked my work, my papers earned C's and D's. I could spell, but I wrote too slowly to keep up with the teacher's dictation during tests. "Try harder," I was told. My blackboard work was sloppy so I asked my parents to buy me a chalkboard. I practiced writing on it and found I had to use my arms differently than when I wrote on paper. One day, Ms. Rhiner told me that she would help me with my handwriting in a few weeks. The promise excited me. I practiced harder and harder. I drew lines, big circles, then large letters that covered the entire board. Often I wrote an "a" backwards; I knew that my right side was towards the storage room door but that did not seem to stop me from reversing letters. Sometimes, when I tried to correct an error I would continue to write the letter wrong again and again and again. I had to wait until my chalk broke before I could stop. (Later, I learned to call these incidents "closed circuits of failure.") When I mastered drawing large letters, I practiced making them small.

Then came the day when Ms. Rhiner offered to help me with my handwriting during recess. She told me to write my name on the blackboard. I held the chalk carefully in order not to break it and I drew each letter meticulously.

Even the "e," the hardest letter in "Dale," was perfect. I stepped back proudly.

"Why Dale," Ms. Rhiner said, "That's very good! Maybe your basic problem is carelessness."

I was so furious I could not reply. I glared at her and ran outside.

"Dale," she called after me, "I'm sorry."

"Carelessness"! I knew that was not my problem. I had worked hard to write well. My handwriting had improved; Ms. Rhiner tore up fewer of my papers.

Then what was the problem? Why did I always wiggle in my chair? Why did my muscles have a mind of their own? And why did I write so slowly?

I thought of the story in one of our readers of Glenn Cunningham, the first American to run the four-minute mile. As a child, his legs had been burned in a fire and everyone told him he would never walk again. But he struggled and one day he took his first step. Everyone was amazed. His mother hugged him and the doctor congratulated him. Everyone was happy. He practiced walking and then running. He practiced and practiced until he ran the four-minute mile.

The story inspired me but it also upset me. Suppose when he had risen from his bed and walked, everyone had said, "Well, now you see what you can do if you try." Suppose nobody had hugged him. Would he have been able to achieve his record-breaking feat?

I studied my hands and legs. There was nothing wrong with them but they just did not do what I told them to. I had to practice and practice like Glenn

Cunningham but my efforts received no recognition. As an adult, I have words for my confused feelings then: I was jealous of Glenn Cunningham's handicap.

It had a name: burned legs. Everyone admired him when he walked. My handicap had no name.

"It helps," I thought, "to pretend I am Glenn Cunningham. When I work hard,

I improve. If everyone says I'm not trying, I must not be trying; and because

I really am not trying, no one helps me. Nobody ever says, "Good girl" to me.

So I'll tell it to myself: "I am a good girl. I am a good girl."

Fifth grade, sixth, seventh, and eighth grade. Time went slowly then. Each second clicked by individually. I hated myself but I never gave up trying.

During the summers, I learned how to swim. The Red Cross taught swimming in four two-week classes. Beginner, Intermediate, Junior, and Swimmer. It took me a full summer to complete each class.

I still had trouble in gym. In team games, I had to choose between doing nothing and infuriating my teachers or trying to participate and infuriating my peers. In gymnastics, I had to walk along a balance beam; I often fell off. My peers changed their methods of teasing me: They greeted me in an exaggerated manner or laughed at me behind my back. In eighth grade, my picture was crossed out of many yearbooks.

My grades were poor. I worked hard but my efforts were not recognized or rewarded; most of my grades were C's. One teacher flunked me, explaining,

"You're getting an E for effort."

A particular incident stands out in my mind. I was practicing throwing a ball against the wall and catching it. A student teacher came over and said, "Dale, can I help you with that? Let's play catch."

"You'd better not work with me," I said.

"Why not?"

"I'm a very unrewarding child to work with."

"What do you mean?"

"I'm unrewarding." After a silence I explained. "Look, a lot of teachers have given up on me. You'll have more fun with the other kids. I'll just frustrate you." We stared at each other and then she turned

away. I went back to throwing and catching the ball. I had caught it 10 out of 10 times. I took a step backwards to see how well I did.

In retrospect, I know that this young teacher thought she was being helpful.

She already had firmly set in her mind the kind of help she wanted to offer but she had no intention of finding out what I needed. I was acting in a determined, disciplined manner, throwing the ball against the wall over and over and catching it, which is rare for a 13-year-old child; she gave me no positive reinforcement for my self-discipline but, instead, interrupted my activity. When she offered to "help" me by playing, her voice was condescending. I knew from past experience with teachers that her patience would not last long. Most teachers had short attention spans, at least when it came to me.

I am also interested, in retrospect, in how I knew that I was an "unrewarding" child. I must have overheard more than one person so describing me - why, otherwise, would the word have come so quickly to my lips?

In French class that year we had to memorize dialogues and recite them. I used to wait in dread for my turn because when I stood up all I could do was stutter. I was given a D in the course and the counselor called me in to discuss the grade.

"I can't memorize the dialogues," I explained. "I practiced every night; I read them over and over, but it does no good. The words fly out of my mind. It must be a mental block."

We spent an hour together and got nowhere. Finally, she said, "Dale, can't you just pretend the dialogues are words to a song?"

"I can't memorize songs either. Every Christmas I try to learn the carols again. I listen. I look at the words, I have friends say the words and I repeat them, but it doesn't help."

We sat silently. How close we were to the core of my problems! However, at that time, the theory that would have explained me to myself did not exist.

Although the counselor could offer me nothing, I thanked her and left.

My high school years also went slowly. The teachers were less alert and less caring, perhaps because there were so many of us in each class and they had troubles of their own. For example, one English teacher was assigned to teach geography. Our math teacher, who had never learned the new math, was told to teach it; every day, before class, the department head tutored her for the next day's lesson. Everything in my life was such a struggle for me at that time that I just stopped struggling to do well in school.

My vision was a problem. Things seemed to melt together so that it was hard for me to find the lock on my locker or a book on a shelf. I had no social skills.

In group projects, such as cooking or putting up a tent, I did not know how to help. And the flow of conversation was difficult for me to master. It took months of watching before I understood how people interrupted each other.

Even so, I could not learn how to use the signals with ease.

When I was admitted to Pitzer College (Los Angeles), I was excited by the prospect of a new beginning. I determined to study hard. I hoped to make new friends; certainly my high school reputation could not follow me. Yet other students still shied away from me. I often ate alone in the large noisy cafeteria because it was difficult for me to recognize familiar faces at a distance while I balanced my tray. People said I ignored them when they called to me. I made a disciplined effort to make friends. I kept a notebook of people's names, classes, and other information and I reviewed the lists each night. I learned to tell whether I was speaking loudly or softly by holding a hand to my throat. Finally, I found some

friends. We always sat at the same table in the cafeteria and frequently we were joined by other students. My group interaction skills improved but most students thought of me as a "weirdo." I could not understand why.

Academically, the college was difficult. In some of my classes I could not seem to hold the necessary facts in my head. By the end of the first semester, I had dropped one course, and had two incompletes and one B. The next semester I not only had to carry on my normal course work but, also, to complete the incompletes. I consulted with upperclassmen and chose easier classes. I gave up my attempts to socialize and worked day and night. By the end of the year, I had A's and one B.

I applied to Antioch College because of their work-study program and their nontraditional approach to education. When I was accepted, I hoped once again to make a new start. The first night there, my roommate Sandy and I talked until morning. On the way to breakfast, we were joined by Betty, who lived across the hall, and several other dorm residents. While we were eating,

Sandy said, "You know Dale, it's funny, but it was easier talking to you last night. Your staring bugs me!"

"Me, too!" said Betty. "I really like you, though. Is something wrong with your eyes?"

"I think so," I replied, "But I don't know what."

"Lots of people stare," said Allen. "It doesn't bother me at all."

"You're not sitting across from her," said Sandy. "I feel as if she's looking right through me."

After breakfast, I went to my Principles of Education class. There were six of us. The professor began an exciting discussion and I had a lot to say, but I could not seem to get my words in. In the middle of the class, the professor said, "Dale, what's happening? You start to talk and then stop yourself."

"I don't want to interrupt anyone," I told him.

He said, "This sounds like a group problem."

The other five members of the class explained that they expected me to interrupt them and they were interested in my views. "How can we help?" the professor asked.

"Well, will you call on me when you want me to speak?"

"Okay. I'll try to remember. Anyone else can call on you, too. Now, how did you react to Tom's comments on free education?"

Antioch College enabled me to socialize. Many students had been through encounter and sensitivity groups and they gave and received feedback freely.

Group projects were common. I learned the things about myself that bother people and I corrected them. I constantly reminded myself to blink and to move my eyes from person to person as each spoke. The movements confused me visually but they made other people more comfortable. I stopped jumping at the slightest sound and turned my eyes and head towards what I wanted to see. In fact, I became tense because of the constant awareness of my body. It was worth it because peers avoided me less.

We went to school all year in four alternating quarters of work and study. Jobs could be taken anywhere in the world. Thus, every three months, my peer group changed. As I improved, my reputation did not drag me back into old behaviors. I mastered conversational signals, after several years, and could speak without interrupting other people. Yet, I always had to strain to understand and keep up. I had to think about what came naturally to others.

And my handicap still had no name. There was no apparent reason for the effort I had to make.

Things came to a head when I was employed as a factory worker at an electronics assembly company. I knew that I would be working on tasks requiring excellent coordination but I felt ready; my vision and motor abilities had improved. I was optimistic that the job would help me to overcome my handicap.

On my first day, Marie, my supervisor, led me into a small rectangular room where two long tables stood in the middle, workbenches were placed against three walls, and floor-to-ceiling shelves lined the fourth wall. Large machines sat on one of the center tables and an oven stood near the door. Marie sat me down at one of the workbenches and started instructing me. When I pulled out a pad to make notes, she objected and I put the pad away. She gave me a razor blade and showed me my task.

I was supposed to strip the encasing rubber and insulation from three wires and then to twist the copper strands slightly. No matter how hard I tried, and despite Marie's efforts to help me, I could not find the right amount of pressure to put on the blade. I cut my fingers again and again.

After four hours, Marie said, "Dale, you've caused too much scrap. You can try again tomorrow. Right now, I'm giving you another job - putting together probes." She took me to a winch. Once again, I took out my notebook and again she objected because "it will take forever if you do." She picked up a metal rod from the table. "Now you put this bar on the winch"-she turned the knob on the side of the winch-"then you screw this top on." The "top" was a large silver ball.

"How did you get the rod to fit in the winch?" I asked.

"I just explained that!"

"Well, I probably wasn't listening while you turned that knob because I needed to see how you did it."

Her face grew grim. She went through the procedure again with a running commentary. When the probe was assembled she stood aside and said, "Now you do it."

I had no idea where to begin. I had forgotten the first thing she said. She prompted me, "You put the rod in the winch."

My eyes, however, could not find the metal rods on the silvery table. When I asked where they were, she retorted, "Right in front of your nose!" She lifted one from the pile in front of me.

I put the rod in the winch and turned the knob. "You're loosening it!" I nodded and switched directions. After 30 minutes of my errors, she let me take notes.

Then it took another half hour while I drew my diagrams. When we finished, she exclaimed, "It took me an hour to teach you what should have taken 10 minutes." I used my diagrams to remember how to put 20 probes together.

Marie informed me that it took the average worker half the time.

I was determined not to become an outcast. I sat straight and proud. I ignored putdowns. I not only avoided verbal replies but made sure my body language remained unaffected. When Marie taught me, I kept my voice matter-of-fact, although I knew my questions were unreasonable. I apologized calmly and took responsibility for my mistakes. I was proud as I improved, yet I remained significantly slower and less accurate than the other workers.

Huge metal racks to heat the probes were on many work tables. One day,

Marie said, "Go to the second shelf from the top of the third set from the left side. On the right of the shelf, there are some plastic drawers and on the right compartment of the bottom drawer, you'll find about 100 bolts. Sit next to Barbara and help her. She'll tell you what she's doing."

I walked towards the shelves, trying to hold the instructions in my mind.

"Dale!" Marie said.

I was so startled I banged into a rack. It was hot.

I looked at my arm. A patch of skin turned red, then white. Then the pain hit.

"Which set of plastic drawers?" I asked Marie.

"Dale, what happened to your arm?" asked one of the women.

"It got burned when I banged into that rack."

"Let me see it," said Marie. "That may be serious. Better go to the nurse." As I left, she said, "You didn't even say 'Ouch'!" She sounded puzzled.

On the way to the nurse, I thought about it. "If you are a klutz, pain is just part of life. You learn not to say anything and hope people will ignore your clumsiness. What hurts you makes others laugh." As a child, I had fallen on floors and banged into walls; I had learned not to react so no one would make fun of me. Then I thought, "Whatever my problem is, it can't be psychological. I don't hate myself this much."

The nurse put oil and bandages on the burn. She said, "It looks like you'll have a scar for about three years. Maybe longer."

When I returned to my unit, Barbara showed me how to put the bolts on the ceramics. It was easy and I could think as I worked. Something was seriously wrong and everyone sensed it. Something besides my vision and lack of coordination was causing problems. I decided to list my mistakes. I wrote them on the pad I used for job numbers and Marie's instructions. Strangely enough, this activity earned me respect from some coworkers. I resolved not to look at my list until my time was up.

On my last day of work, Marie said, "I guess you got mad at us sometimes and we got mad at you. But I really hope it wasn't too bad."

"I hope it wasn't too bad for you," I replied. "Thank you for your patience."

I left feeling relieved, upset, and guilty.

In my apartment, I studied the error list. Over half my mistakes involved hearing. Hearing! I knew that my vision and touch were off. I knew I was clumsy and had no sense of direction. But I had assumed that my hearing was safe. I knew then that I could trust none of my senses. I was depressed for days. When my depression did not lift, I made an appointment at the college counseling center.

"I had some problems on my last job," I explained to the counselor, "and I hoped talking to an adult might help." I told her everything that had happened, and showed her my list of errors. "My boss always yelled at me.

She said it took me too long to learn things. I was so clumsy I cut my fingers with the razor blades and burned myself severely." I showed her the scar.

"Anyway, I'm here because I don't know what's going on. My unconscious mind can't hate me this much! I feel upset, but I don't feel crazy."

She asked me many questions. Finally, she said, "It sounds to me as if you might have perceptual problems. Your hearing difficulties sound like auditory sequencing problems."

"Auditory sequencing problems?" I questioned.

"Problems in hearing sounds in the right order. That's why you always have to write down what you hear. Our staff can give you the Wepman test of auditory discrimination." (I scored in the lowest five percent in my ability to hear sounds over background noise.)

The counselor continued, "Your visual and auditory problems and inability to tell right from left sound like perceptual problems, trouble taking in information through your senses. You really fit the constellation well. Why don't you read a textbook on learning disabilities? Most of them have a section on perception. I wish there was more I could suggest, but there are really no tests for people your age."

At the library the next day, I found that there was no catalogue category for learning disabilities, so I went to the special education stacks. I found plenty of material on physical and mental handicaps but nothing I could identify as my area of concern. After several hours of browsing, I came upon *Psychology of Exceptional Children and Youth* (Cruickshank, 1963). One chapter was called "Psychological Characteristics of Brain-Injured Children" by Cruickshank & Paul. I had to read it several times before I could fully absorb the contents.

The characteristics described by the authors appeared to be a problem-by-problem profile of myself. Hyperactivity ("always in motion and – always double time"). Hyperdistractibility ("inability to focus attention selectively on one major aspect of a situation – overresponse to external stimuli and "overresponse to internal stimuli"). I thought, "So that was why they always said I wasn't paying attention!" I looked at the wall in front of me. I had learned always to study in isolated places where I was not distracted by the passage of people and the rustling of pages. Perseveration ("the lack of impulse control of a motor act of some kind"). I remembered writing the wrong letter on the blackboard over and over and over again - "closed failure circuits." Lability of affect (emotional instability; overreaction). The chapter described a 10-year-old girl who burst into tears "accompanied by loud sobs" when she accomplished a task upon which she had been engaged for several days. I was not surprised. "Maybe she had been working on it for months which the researcher didn't know about," I thought. "Even the researcher didn't understand that it was normal for her to cry; these handicaps can be hard and frustrating." Motor dysfunction ("difficulties in gross and fine motor movements – the inability to move one's body in a synchronized and integrated fashion"). No wonder I was such a klutz!

Later, the chapter explained the perceptual distortions that afflict the brain-injured child: "figure ground disturbances "the brain-injured child is unable to attend to the figure. The background becomes highly distractible to the child and he is forced to respond to it." I wondered if that explained why my vision seemed to melt things together and why I had trouble seeing a dish on a shelf or a knob on a piece of equipment. Auditory problems ("sounds run together and are not integrated into a meaningful sequence or pattern").

All my problems had been described in the 20 pages of the chapter. I was not crazy. I had an identifiable medical syndrome. I was not alone any more.

Looking back, I could identify the attitudes which had helped my development and those which had hindered it. I had not been diagnosed as a child. It is quite likely at that time that school personnel and doctors did not know about my minimal brain dysfunction. This fact, perhaps, helps to explain the swiftness and harshness of people's judgments. My low performance was always seen in terms of "carelessness" and "not trying," an attitude that led to a workload which was heavy almost to the point of cruelty. Because I was funny-looking and not socially adept, my peers had teased me a great deal.

The same elements that made me the butt of my peers created problems for me with some teachers. As I grew older, the overt teasing stopped but people avoided me.

People with a visible disability are given positive reinforcement for what they can do. We admire the person in a wheelchair who travels around the country in a motorized van or the blind television talk-show host; the blind person who learns cane mobility receives positive reinforcement from the teacher. On the other hand, people with invisible handicaps are expected to attain the norm without effort. They rarely receive credit for their attempts; they are criticized for having trouble in the first place.

I recommend that parents and teachers of learning disabled/minimal brain damaged children talk frankly about the handicap and its manifestations and express confidence that the children can handle it. It is important to recognize and reinforce the discipline it takes a person to overcome this handicap.

Ironically, a direct challenge (i.e., "You will never learn to drive a car") can be more motivating than the serene belief that one can achieve something easily (i.e., "You could read that if only you tried a little harder"). A helpful approach when an LD student is having difficulty with a task like math might be to say "I know you're having trouble with that math. I like the way you're working hard at it. Do you think you can finish seven problems by the end of the period? That way, you would do even better than yesterday!" Sincere approval is very motivating.

Specific feedback, whether negative or positive, helped me. For example, at Antioch, for the first time, people stopped and analyzed what it was about me that bothered them. Sandy, who told me not to stare, and my factory supervisor, who let me know exactly how I compared with other workers, gave me useful information. Lenora Johnson, my fourth-grade teacher, was the person who started my career as a writer. It helped me when my professor in Principles of Education stopped the class to find out why I was starting to speak and then stopping myself. What was happening was that as soon as I got the words ready to say, someone else was talking. The behavior had occurred in many groups, but that professor was the first person to encourage me to participate. He also encouraged everyone in the class to help me, setting the stage for acceptance rather than rejection.

The counselor who tried to understand why I got a D in French gave me sympathetic attention which was helpful. It is too bad neither of us were able to generalize that I had trouble remembering what I heard.

My parents never lost faith in me and gave me a tremendous amount of support. My mother taught me how to read. Despite my many hair-raising escapades, she guided me with a firm hand but never overprotected me. My father helped to teach me how to drive. He helped me to develop social skills by role-playing critical incidents.

Perhaps the counselor who told me that she thought I had perceptual problems was the most helpful character in my story. Learning about my problem changed me from a person who hated herself to someone who likes herself and knows that she is struggling with a real handicap. My problems have not changed but my attitude has.

Reference

Cruickshank, W. (Ed.). Psychology of exceptional children and youth (2nd ed.). Englewood Cliffs, NJ: Prentice Hall, 1963.

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