

# DISABILITY: IN THE EYE OF THE BEHOLDER

David Prichard, Ph.D., University of New England

In this personal narrative, the author recounts his experiences with 'differently-abled' children that have come to form part of the bedrock of his understanding about people and relationships, and have helped him to understand some of his own strengths and challenges. The author feels that the lessons learned in his personal and professional life inform him more than any of the academic texts he pored over in graduate school.

This article is dedicated to my sister, Tara, who in her own way taught me about letting go and about unconditionally trusting others.

## Blind Trust: Letting Go

Tara, my younger sister, was adopted when I was 12 and she an infant. Blind since birth due to a congenital condition, Tara, in her youth, epitomized independence. She did not know she was 'different' from other children until she started kindergarten. We lived on a rural farm and Tara had the house pretty well mapped out in her mind. As a toddler, she would go tearing around the house, stopping moments before hitting a wall or piece of furniture, her footfalls echoing off the objects and serving as her 'eyes' as she played.

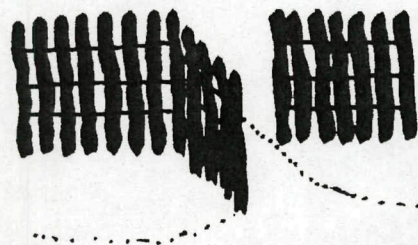
Tara was very special to me. With her curly blond hair, blue eyes, and infectious smile, she would light up any room she entered and drew natural attention. Her age and sightlessness conspired to make her face an open book. Her emotions and feelings would flutter unchecked across her face, her sightless eyes scanning this way and that as she processed her world. Her eyes would 'gaze' in one direction or another depending on the information she was processing and whether she was thinking or feeling. Decades later we recognize aspects of these phenomena as crucial to clinical work using Eye Movement Desensitization and Reprocessing (EMDR).

When my mother left the family and started a new life as a migrant farmer on the West Coast with her new husband, my two brothers and I were left to parent then six-

year old Tara. During the next six months it became increasingly clear that we were woefully unprepared to care for a young child and that Tara needed more traditional parents. We arranged for her to move 1500 miles away to the deep South to live in a trailer with her adoptive father, my past step-father. I was elected to take Tara to the airport, a two hour drive. I skipped my high school classes and spent the day getting Tara packed, trying to suppress the numbness and pain that I felt as I prepared to say goodbye to my sister.

Tara grasped my hand and happily bounded up the ladder to the plane. As I helped her get settled in, I knew full well that I likely would not see her again for quite some time. My mother's second divorce had been a difficult one and I had never bonded with my past step-father. Tara was excited by the adventure of the plane ride, unaware of the significance of the trip and that the connection she had known with me was forever changing at that moment. My heart breaking, I held myself together as I hugged her, said goodbye, and left Tara in the care of a nameless flight attendant. Later, I stared stone-faced and numb as I made the drive home. I did not have any communication with Tara for the next 15 years.

The call on my answering machine startled me. I had lost track of Tara through the years and had no idea where she was living, other than 'down South'. For years I had carried around the guilt of 'abandoning' Tara and feeling as though I had somehow violated her





trust in me by not making a stronger effort to maintain contact though the years. Heart pounding, I returned her call. I could still imagine her as the slight six year old I had felt forced to abandon, myself a child, so many years ago. The voice was unmistakably hers, and we had an engaged, animated conversation. While my last memory of her had been one of pain and anguish, Tara, understandably, had no recollection of our parting.

I arranged for Tara to attend our next family reunion. I picked her up and we had several hours in the car together driving through some of the more remote areas of New England. Tara had matured into a confident, self-assured young adult, and I was overjoyed to see the same enthusiasm and self-confidence that I had seen in her as a child. During the ride, I described much of the beauty that I was able to perceive in our surroundings, including several moose that we passed during the trip. We talked. As we drove, Tara experienced the beauty of rural New England through my eyes; I witnessed the memories of her childhood through her 'eyes'. With this re-connection, I was able to supplant my last memory of my sister, saying good-bye on the plane, with a fresh, updated and recent memory. Her contact with me was more of a gift to me that she could ever know.

Tara was received with open arms by my siblings at the reunion. Her adventurous spirit ever present, she now was ever curious about her surroundings and wanting to 'join' with the family as if to make up for the 15 years that she had been absent from us.

One of our annual family traditions included jumping off the cliffs of a narrow gorge into deep pools of water far below. The paths to the cliffs were rocky and crossed with gnarled roots. As we made our annual trek, Tara was full of questions and unhesitating in her desire to join us in this feat. Critical to the jump was judging distance – jump too short and risk striking the wall on

the way down; jump too far and risk landing in the shallow waters on the other side of the gorge (it was that narrow!). Tara wanted to jump and would not be deterred. For me the jumps often required a leap of inner faith; for Tara it would be a leap of faith and trust in others.

"I want to jump too. Let me see the edge." Tara used vision-oriented words – they simply held a different meaning to her than that held by most of the seeing world.

"Really?" I asked, surprised, doubt showing in my voice. Here was the trusting child I had been put in the position of abandoning on a plane 15 years ago, and now I was helping her jump off a narrow gorge.

I led Tara up the path to the edge of the cliff where she gripped her toes over the edge and cocked her head to one side. She was listening to the sound of the water cascading off the falls below and the calls of encouragement from my two brothers who had gone before. I recalled the expression lovingly – how often I had seen it in Tara as a child. It was her way of judging distance by an acute sense of sound. She turned her face toward mine, laughed lightly, and jumped.

When it was time to return Tara home, I drove her the 13 hours down the East Coast to what was then my home. We caught up on her life over the past 15 years. I remember putting her on the train at the end of the visit. She had grown to a mature, intelligent and attractive young woman. Full of self-confidence and self-assurance, Tara had maintained the independence and trust that I had loved so much in her childhood. I flashed back to putting her on the plane so many years ago when I believed that I would never see her again. This time I held her close, said goodbye, and as I drove home, sobbed the tears that had been 15 years in coming.

What did I learn from Tara over the years? Most importantly, I learned trust as I watched her trust other people with such total abandon. First as her mother left her, as a six year old,



in the care of her older siblings, and many years later as I led her to the edge of a cliff to jump blindly into the abyss below.

I would like to be able to say that I have learned to trust and to 'let go' with half the abandon that she is able and willing. I do know that the letting go of control involved in trusting relationships has been an issue for me for much of my adult life. In my clinical practice, much of the work I do with clients, particularly those with trust and control issues, focuses at some point on 'letting go'. I am so often reminded of the need of my clients to 'let go' of their grip on parts of themselves that are no longer helpful, to release old memories and experiences, and to jump, sometimes blindly, into that deep abyss. It is in trusting ourselves to jump into the deep abyss that we can truly learn to soar to great heights. I witnessed from Tara the courage to leap blindly into the abyss. I reflect on Tara's leap often as I work with clients who ask me to act as a guide as they are leaping into their own emotional abysses. And I reflect on Tara, at times, as I leap into my own abysses in life.

### **Independence: In the Eye of the Beholder**

When I was a child my family took in a number of physically challenged children through the state foster care system. Some of the children had passed through our home a matter of months while others had stayed involved with us for years. As a young child, I quickly learned that all children, as well as adults, are unique and individual in their varying levels of physical ability. Each of us has some areas that challenge us and others in which we excel. My early life experiences, first with my sister Tara and later with the other 'disabled' children in my family, had a profound impact on me and contributed to my devoting the early part of my career to helping physically challenged children.

I went on to be employed as a member of the counseling staff at a federally funded

overnight camp for children with disabilities. Children at the camp would arrive with mental and physical diagnoses including cerebral palsy, muscular dystrophy, deafness, blindness, and developmental disorders. The mission of the camp was to provide children with an outdoor summer experience that would parallel, as close as possible, what non-disabled children experience at summer camp. Campers were involved in boating, camping, canoeing, swimming, arts and crafts, music, and sports. For many of these children the summer camp experience was one of the few opportunities they had to be in a 'normal' environment participating in 'normal' activities where they did not feel 'different' or 'abnormal'.

### **Active Listening: When Words Are Not Enough**

When I first met Brian at camp, he was peering at me over the top of his tortoiseshell glasses. An impossibly slight eight year old, he sat contorted in a small blue wheelchair, his body ravaged by cerebral palsy. On top of his chair sat a manual communication board with pictures associated with words. Though it was laminated, it was clearly worn with age and use.

Over the next two weeks, Brian and I would become largely inseparable, as I wheeled him to and from various activities and meals. Part of cabin responsibilities included dressing and assisting the children in personal hygiene and showering. Boys had no privacy in their cabins; the bathrooms had no stalls and three shower heads lined one wall. Brian never complained as he was carried into the shower room, though he did request to shower after the other boys were through. He was as light as a feather and his small body easy to wash as there was so little of it.

Toward the end of the two weeks, I became alarmed when Brian became feverish and lethargic – this was unusual for him and I was concerned that he was coming down with



the flu. I instructed one of the other counselors to remain with Brian in the cabin and have a nurse evaluate him, while I attended to the rest of the children who were scheduled for an overnight boating and camping trip.

Before leaving for the overnight, I checked on Brian in his cabin. He was curled in as close to a fetal position as his stiff body would allow.

"I'm sorry you're not feeling well, Brian. I know how much you were looking forward to the camping trip."

Brian jerked his head in affirmation. Whenever he was away from his wheelchair, Brian lost his 'voice'; his communication board which was attached to the chair. At these times, Brian could not communicate except with his eyes and facial expression.

"I've asked Tom to stay here with you, and the nurse will be checking in on you. Is that all right with you?"

Another affirmative nod. And a beseeching look.

"Is there something more?" I asked.

Brian looked at me, then his chair, then at me, and again his chair.

"You want to come with us?" I asked compassionately, trying to interpret the meaning in his eyes. "You really don't seem well enough for that, do you think?"

He looked at me again, his bleary eyes opening wider, seeking my understanding, and clearly wanting to communicate my misunderstanding. Again he looked at his chair and then to me, his face straining.

"Hang on a second" I said, and quickly disconnected the communication board from his wheelchair. The board was a large tabletop that attached to the top of Brian's wheelchair. It had the alphabet displayed on it, and a handful of nouns, verbs, and subjects spelled out. When seated in his chair, Brian would also use the board as a table for eating and for resting his arms and head.

I rested the board awkwardly on the bed and adjusted Brian so that he could reach the

board with his right hand, the hand with less spasticity.

"C . . . a . . . t . . . c . . . h . . . f . . . i . . . s . . . h . . . f . . . o . . . r . . . m . . . e . . ." he spelled out laboriously, then looked at me with a mischievous smile.

I laughed, as I settled Brian back into his bed. "Will you help me clean it if I bring it back?"

Brian smiled, cocked his shoulder in his version of a shrug, then jerked his hand, his familiar way of saying 'conversation over' and 'see you later'.

It was a beautiful night for camping out, and I thought of Brian as the other boys and I toasted marshmallows that night. His cerebral palsy was a result of forceps squeezing his head during delivery and the resultant brain damage that he suffered. He had an IQ that tested well above average, and despite the severity of his disability had been mainstreamed into the public education system. What struck me most about Brian was his ability to communicate non-verbally, a skill he had to rely on due to the impact of the extreme spasticity of his condition on his vocal cords.

When I returned to camp the following night, I stopped by the nurses station before heading back to the cabin. I was curious about Brian.

"Well, actually he is doing much better," Sue responded to my inquiry. "Looks like his problem was an intestinal blockage, and after we cleared that out, his fever started to go down, and he's starting to feel better. One more enema this morning should fix him up."

"Great," I replied. "We missed him at the overnight, and it's no fun for him to be stuck in bed."

I dropped off the overnight gear and equipment in the camping shed and walked back to the cabin, where I encountered the usual chaos of boys chattering and laughing as they got re-settled into their cabin. Brian's



bed was empty. Curious, I checked the bathroom.

Brian was wedged under the arm of a cabin counselor, his crooked legs dangling. Tom was holding him naked while fumbling to open a package containing the enema Brian was scheduled to receive. I noticed that two other boys were in the showers and a third was washing his hands at a sink.

Brian's eyes immediately locked onto mine, his eyes filled with anguish.

"Brian, we missed you. Are you all right?" I asked, my voice full of concern.

His eyes moved repeatedly and with great determination between my eyes, and the package that was now opened. His face, red with emotion, was a mix of embarrassment and anger. Brian stared at me beseechingly, imploringly. I paused.

"Tom, hold on a second, will you? Brian's very uncomfortable, and he's trying to tell me something."

"What is it Brian?" I asked. He looked at his legs and back at me, then at his legs and back at me. I wrapped him in a towel and took him back to his cubicle, where he could communicate with me using his board.

He was in such an agitated state that it took him longer than usual to control his spastic arm movements to spell out to me his feelings.

"d . . . o . . . n . . . o . . . t . . . w . . . a . . . n . . . t . . . b . . . o . . . y . . . s . . . t . . . o . . . s . . . e . . . e . . . m . . . e"

After he spent several minutes of frantic and belabored pecking on the communication board, I finally understood out what he was communicating.

"You want to be someplace where the other boys can't see you?" I said. "Of course, you do. I'm so sorry. I'll dress you and take you to the nurse's station and we can take care of things there."

Brian gazed at me, relief apparent in his eyes.

Brian taught me valuable lessons in communication and in human dignity. First, communication is so much more than what is verbalized through our vocal cords. Brian had developed an exquisite ability to use his eyes and his facial expression to communicate to others. Because the process of pecking out words was so laborious, Brian relied on others to interpret the gist of his messages and to elaborate with questions. Second, regardless of one's physical challenges, all people have pride, self-possession, and a need for privacy and to maintain self-dignity. Tom had insensitively generalized Brian's acceptance of the group shower and bathroom with a comfort in being handled to receive an enema in front of his cabin mates. I can't imagine many people, particularly a pre-adolescent boy, wanting to receive an enema in full view of his friends.

Years later, I saw Brian at the university where I teach. He was enrolled as a student and had a full-time companion to assist him in his studies, transportation, and other activities of daily living. His communication board was now electronic and his wheelchair electric, but the sharp tilt of his head and the peering of his eyes from under his crooked glasses was unmistakable. I wondered if he knew how much I had learned from our time together at camp and if I had imparted lessons of any greater import.

### **Intentionality: It's the Thought that Counts**

Jenny was eight years old, with a wide smile. Rail-thin, her body was usually contorted with the ravages of spastic cerebral palsy. I first met Jenny when her father came driving a large logging truck down the steep dirt road leading to the camp. He was a big man with a barrel chest and large rough hands. As he pulled up to the welcome building, I noticed a small girl in the seat beside him. Her father effortlessly lifted Jenny from the passenger seat, and held her under one arm



as he lifted the wheelchair off the back of the truck with the other arm.

I came to know Jenny well over the next two weeks. Always with a ready smile, she was friendly and extremely bright. Although she was unable to speak due to the spasticity of the CP, Jenny was able to communicate with her eyes, with her smile, and with sign language. The sign language was a challenge due to the mild spasticity of Jenny's arms. Though Jenny could walk, this too was difficult and she usually relied on the wheelchair to assist her. Over the course of the two weeks Jenny spent with us, I saw the wheelchair less and less, as Jenny appeared to lose her self-consciousness about walking. I remember frequently seeing her walking across the campgrounds, her body jerking like a marionette.

Jenny danced like she walked. And it wasn't until I danced with her that I really came to understand Jenny and learned to see past her physical challenges. On rainy days, the recreation hall would convert to a dance hall, and campers and counselors would quickly fill the space, escaping the gloom and dampness of dank, darkened cabins. That day, there was a downpour. I arrived early, and the hall was already full and buzzing with excitement as I entered. Several counselors were dancing with one another; some with campers. Sylvia was dancing a slow dance with Brian, swirling him around and around in his wheelchair, Brian, glasses skewed, holding on and laughing.

Toward the back of the hall, Jenny sat alone, looking bored and distracted. She was slouched in her wheelchair. Her limbs though unusually relaxed and still, were rigid and looked unnatural – arms crossed straight and stiff in her lap, legs flayed in two different directions. As I approached from the side, her face lit up, and Jenny opened her arms in her familiar welcome. Her infectious smile matched the excitement in her eyes.

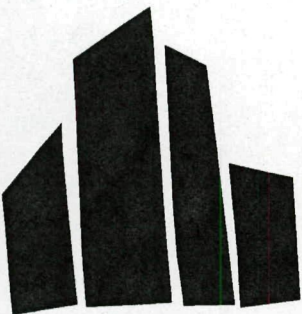
Jenny loved to dance. At camp she could dance without feeling different, without feeling self-conscious, and without being stared at.

"Jenny ...what, not dancing yet? Or are you already tired?" I teased. She laughed and struggled out from her chair, limbs flailing. Like many people with cerebral palsy, spasticity seemed to increase with excitement.

I offered my hands and we made our way to the floor. Dancing was the only time that I noticed a relative fluidity to Jenny's movements. Perhaps it was that her spastic movements could be interpreted as dance movements, but in any case, the more she danced, the more Jenny looked like everybody else on the dance floor. I believe that it was one arena where Jenny could be different and physically expressive; her unpredictable body movements could be attributed to her dancing rather than pathologized as spasticity. And like all the other dancers on the floor, Jenny could only communicate with her eyes and her smile; even if she were she able to speak, her words, like everybody else's, would have been lost quickly in the din of the music. Dancing fit Jenny – flailing limbs and no words were the norm, and communication occurred largely through eyes and smiles.

One of my more poignant memories of Jenny occurred at the end of the camping session. Jenny was waiting for her father who was due to arrive shortly. We had just finished singing and signing our favorite song "Leaving on a Jet Plane." Though Jenny was unable to speak and her arm movements were spastic, she loved to sign songs, and this was a favorite.

As we completed the song, Jenny's favorite counselor, Sylvia, walked by, clapping at our rendition. Jenny smiled broadly and opened her flailing arms wide, interpreted as asking to give and to receive a hug. They embraced and Sylvia almost immediately let out a scream. Jenny's hands had involuntarily locked onto Sylvia's hair and she was





spastically yanking and tugging. The more Jenny tried to stop her flailing the more spastic she became. Her body contradicted her intent.

Jenny's eyes locked onto mine; tears rolled down her face as a large tuft of hair came off Sylvia's head. I compassionately restrained Jenny's arms, and Sylvia gently pried Jenny's fingers from her scalp, tears of love and pain running down her face. The love and the pain in Jenny's eyes remain with me to this day, as she inflicted this unintended pain on someone about whom she cared so deeply.

What I learned from Jenny more than anything is the importance of intention in communication and in interaction. Jenny was more able to let me know her true intentions and the meaning behind her behavior than many adults I know who have full use of their vocal cords. There was an incredible depth of love and caring in the interaction, certainly more than might be suggested by the behavior to an unknowing and naïve bystander.

Jenny also taught me about incongruence in communication. Frequently her eyes and smile would convey one message while her body another. When Jenny became excited, her spastic movements would increase. On more than one occasion I would hold her in my arms while her limbs flailed about uncontrollably. For Jenny, the intention on her part of a hug could quickly turn into a flailing assault. Though her body would betray her mind, her normally sparkling playful eyes would show clearly her intent.

Jenny taught me that intention counts, sometimes more than behavior.

### **Disability: A State of Mind**

I was hungry after an afternoon of playing soccer and looked forward to dinner. Friday was spaghetti night at the camp, and I was ready for a carbohydrate boost. Walking into the dining hall, I made my way over to Michele's table. She was sitting beside Brian and was busy feeding him. Twirling the

spaghetti with fork and spoon, she would lift his head and place the fork of food into his mouth. I had not seen Brian since that morning and was pleased to see him. He was seated in his familiar blue wheelchair, his communication board serving as his food tray.

"Brian, great to see you!" I exclaimed. "May I join you?"

His head bobbed in affirmation, blue eyes twinkling and peering out under his tortoiseshell glasses. He peered again at Michele, his way of saying, "Another bite, please."

"Are you up for the canoe trip this afternoon?" I asked. Brian looked at Michele, then at me, and then at Michele again.

"Michele's taking you? Great...maybe this time you'll catch some fish," I teased.

I pulled out the chair across from Michele and sat.

"Yup, we're heading up Pepper Creek and out into the main branch of the Ojibwa River. I hear the fish there are jumping," she offered.

"Man, you gave me a run for my money out there! I thought we had you for a while, but the push for that last goal really did me in," I said to Michele. "You ran circles around us..."

Michele chuckled. "It's all in the footwork, you know, all in the footwork..."

Complying with Brian's eye request, Michele deftly twirled another forkful of spaghetti. Brian jerked his head and strained it toward his glass of milk, his eyes flickering between Michele and the milk.

"Ah, milk it is then," Michele said, acknowledging Brian. She put down the fork, picked up the glass and carefully gave Brian a long drink, dabbing his chin with a napkin as some milk dribbled down, as it inevitably did.

Brian looked from me to Michele and back again, his familiar way of telling us that he was engaged listening to us and wanted us to continue our conversation.



I paused for a bite, and then continued. "Well, to be fair, I do think that our teams were a bit unbalanced. I mean you were a member of the past high school state championship soccer team."

Michele laughed. "I think you just don't like being beaten by a girl." Brian joined in the joke, his lips stretched wide, his back arched, his way of laughing.

We finished dinner quickly, and Michele and Brian got ready to leave. Michele stood, pulled Brian away from the table and wheeled him through the dining hall toward the door.

Michele has no arms. A tragic result of the Thalidomide fiasco of the fifties, Michele had been born with no arms and a fighting spirit to live with her abilities rather than her 'disability'. Michele had been a camper at the camp for many years as a child and over the past couple of years had returned first as a counselor and then as the sports director. I remember fondly her facility with soccer balls. Her feet served as her hands, and she was as capable as anyone in feeding children that needed feeding and caring for campers. I recall driving through a toll both with Michele once and the look of surprise on the attendant's face as Michele reached her foot out of the driver's window to deposit two quarters into his hand. Her van had been retrofitted to accommodate her, and Michele drove with great facility with her feet only. Michele has since married and has several children.

Michele taught me about focusing on our abilities rather than our 'disabilities'. Rather than concentrate on what was lacking in her life and what she was not able to do, Michele had unique abilities that allowed her to excel where others could not. It was here that Michele put her focus.

### **Death & Dying: Living in the Moment**

It was the first night of camp, and that evening we were being greeted with a beautiful dusk. The sun was settling gently over the small lake, the sky a vibrant orange

reflecting off high cirrus clouds. I sat on the gently sloping hill of the camp. From here I could see much of the main grounds: the large A-frame cabins to the left and right of the lake front, the familiar horseshoe shape of the waterfront dock, the raft floating out beyond the docks, two pontoon boats used to transport children around the lake.

I reflected on my past two years here. For so many children, the camp experience here was one of the few times in their lives when they could feel as though they fit and were not different from other children. Diagnoses ranged from muscular dystrophy, cerebral palsy, and spina bifida to blindness, deafness, and amputations. There were also children with developmental conditions, including mental retardation and autism. The camp is carefully and specially designed to allow participants to be able to do all the things non-disabled children do at other summer camps. There is boating, camping, swimming, arts and crafts, athletics. I'd been amazed at the level of accommodation provided to assure a safe and 'normal' camp experience to children with the full range of physical and mental challenges. What struck me the most was how quickly folks at the camp learned to see beyond the 'disability' to the many other dimensions of the children. These were children, and except for their disabilities, they were just like any other children.

I was shaken out of my reverie as the door to a distant cabin opened and a lone figure emerged. It took me a moment and a double take to recognize one of my favorite campers from the previous year. Sara, 12, was outspoken and very bright, and had a wonderful, cheerful sense of humor. Her long brown hair was usually pulled back into a ponytail, and the summer sun accentuated the brown freckles splashed across her face. She was walking awkwardly with metal crutches and moving slowly along the path toward me. I was struck most by the fact that she was alone and that she was on crutches. Her



cerebral palsy was relatively mild, but had confined her, last I knew, to a wheelchair all her life.

"Hi, Sara," I called to her as she neared. "I see that you've had some changes in your life..."

Sara balanced herself carefully on one crutch and waved an arm.

"No more wheelchair!" She exclaimed, her face beaming. "The last surgery and a year of physical therapy...I can't wait to see Nancy. She's going to be so surprised. I told the doctor that I had to be on crutches for camp, I just had to..." She paused, catching her breath. "You haven't seen her have you?"

I laughed. "Sara, it's so good to see you, and I'm so happy at your great news, truly happy for you. And, no I haven't seen either your doctor or Nancy," I teased. "Maybe she'll be in later this evening. I imagine that she's in your cabin again?"

"I hope so...I just can't wait for her to see me walking!"

I stood and smiled. "Come on Sara, I'll walk you to dinner." As we maneuvered the path to the dining hall, I marveled that Sara was walking by my side assisted only with crutches.

That night I slept fitfully, some concern tugging at my consciousness. I couldn't get Sara and Nancy out of my mind. The best of friends, the two were often seen traipsing around the grounds of the camp in years past. They had been inseparable. Nancy, 13, was a contrast to Sara – quiet and shy, blushing easily when spoken to. Her blond hair was short and cut in bangs across her forehead. She had led a fairly normal life until two years ago when her coordination had started to deteriorate and she had been diagnosed with muscular dystrophy. Last year it had been difficult to notice anything remiss with Nancy, except for her slightly awkward gait, a telltale sign of muscular dystrophy. Nancy had appeared particularly pleased with her caretaker role with Sara; the wheelchair also

served to provide added support for Nancy, who had struggled with her diminishing ability to walk without assistance.

Children with muscular dystrophy were perhaps the most difficult for me to work with. This disease takes young lives. At the very age when children's bodies are growing and coming into full bloom, they wither and die. I wondered how far Nancy's disease had progressed during the past year, and how she might react to Sara's improvement. Eventually, I fell into a troubled sleep.

My fears were realized the following day. Nancy arrived during the lunch hour, and I was devastated at the deterioration in her physical functioning. Confined to an electric wheelchair, Nancy barely had the strength to lift an arm to control the toggle switch to maneuver the chair. I noticed that not only did Sara and Nancy not sit together, they sat at separate tables.

I happened upon Sara later in the day and asked how her reunion with Nancy had been.

She broke down. "She won't even talk to me. I'm her best friend and she won't even look at me. She hates me...hates that I can walk and she is stuck in that stupid chair." She paused. "After all the times she pushed me around, she won't let me anywhere near her chair, I don't know what her problem is."

Sara was devastated. We talked for quite some time, Sara fluctuating between crying and anger. She was clearly confused and upset by Nancy's rebuff of her. It was a complex issue for the two girls to be dealing with. Sara's physical improvement was in such stark contrast to Nancy's deterioration. Sara would continue to improve; Nancy would wither and die within a couple of years. I felt a deep sadness that two girls so young had to struggle with such profound issues at so young an age.

The girls did re-connect by week's end, though it took a terrible tragedy to bring about the reconciliation: the death of a fifteen-year-old junior counselor. Mark, an aspiring long



distance runner, had been jogging along the camp road when the father of another counselor struck him down while driving back from town. It had been a glancing blow, but Mark suffered severe head trauma and died on the scene. It was a devastating time for everyone at the camp, and a tragic irony that death would visit us in such an unexpected manner.

I never saw either Sara or Nancy again after that summer. I did receive a notice in the camp newsletter a year later that Nancy had died, finally succumbing to the ravages of her disease. She was 15. I suspect that Sara no longer needs her crutches and is likely walking unassisted. I really don't know what the future holds for us, none of us. Whether we are living with a terminal neurological condition like Nancy, struggling with a lifelong medical condition like Sara, or are young and healthy like Mark, life may be snatched away from us at any moment, in the twinkling of an eye.

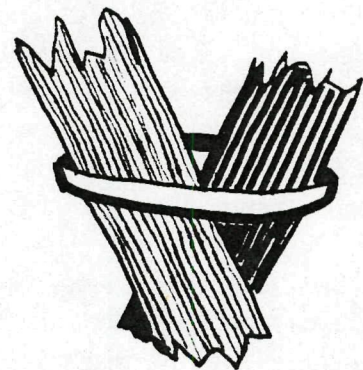
### Lessons Learned

My exposure to and experiences with family members with physical challenges have taught me so much. My sister Tara helped me to understand that our bodies will compensate for limitations in other areas. For Tara, this manifested in developing an acute sense of hearing. She can tell if I have lost (or gained) weight, down to the pound, simply by hearing the sound of my footfalls on the floor. While I may have a strong sense of sight, Tara's sense of hearing is a hundred times more acute than mine. Tara also taught me about trusting others unconditionally and relinquishing that elusive, fictional sense of control. Tara could not have experienced the thrill of jumping from the cliff without her willingness to let go of control and rely on trust. In my life, I have struggled mightily with maintaining the illusion of predictability, control, and self-reliance. I cannot experience the multi-dimensionality of life and all it has to offer without giving myself over to trusting and

believing in the competencies and goodwill of others.

Perhaps the most profound impact of these life and professional experiences have been an increased understanding that physical limitations are not the only limitations that restrict, challenge, and limit independence. Mental challenges have at least as great an impact and are potentially as restricting as are physical challenges. In my extended family, I have witnessed the internal prisons and self-confinement that occur with the debilitating effects of posttraumatic stress, obsessive compulsivity, and agoraphobia. I have seen the impact of phobias, panic, and depression on loved ones. Physical challenges present very real obstacles to achieving independence for some individuals; likewise, mental challenges provide equally challenging barriers to independent and self-reliant living.

David Prichard, Ph.D. is an Associate Professor at the university of New England School of Social Work. Questions or comments regarding this article can be addressed to: [dprichard@une.edu](mailto:dprichard@une.edu).





Copyright of Reflections: Narratives of Professional Helping is the property of Cleveland State University and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.