

To Become Our Own Person

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Symposium editor's note: This article is presented as commentary and not as a scholarly article.

Childhood is a riddle. Growing up in small town America in the 1950s made this puzzle more complex. What is usually viewed as the simplest of times in this country was anything but simple for me. Looking in from the outside, our family appeared typical; four children, working father, stay at home mother, no locked doors, one dog and bicycles pieced together with old parts. No fences and everyone knew everyone and there appeared to be no secrets. I learned in adulthood there were many secrets and hidden agendas.

In fourth grade, my hearing was tested. The school nurse asked me a question with an elusive answer. "Do you realize you have a significant hearing loss?" She said she would inform my teacher and parents. Being so young, I did not know what to expect. I waited. I noticed I was moved to the front row in class and the teasing at home continued. When I misunderstood or repeated something incorrectly, ridicule followed. I didn't know what questions to ask or who I should talk to about how I was feeling. I remember feeling very lonely and isolated. This was difficult for me because I was, and still am today, a very outgoing person. Often I misunderstood even the simplest directions in class or when I was on the playground and game instructions were given. Often I reacted, answered a question or played the game wrong. I assumed I was ignorant because I only knew living with a hearing loss. I don't think I ever heard "normally."

The same people whose trust I should have treasured were laughing at me. I felt alone at home as well. Yet I was dressed in pretty dresses and shiny shoes and sent to school and church *looking* perfect while feeling confused. Looking back on those days, I believe the underlying message being given to me was to hide "imperfections." I was being taught to appear perfect, as society must have expected. To keep anything that might set me apart as a secret.

In the 1950s, I have learned, only hearing aids with wires to a bulky box would have been an option. I might have heard better but appeared odd to others. I have talked with several people that wore this type of apparatus as youngsters and they did feel odd. But when I would question them, I discovered that their families supported them and worked through this societal dilemma with them. One secret in my life was that I could not hear well. I apparently was not to discuss this with anyone, even as I grew older.

In retrospect, I realize that not hearing well was, at times, rather comforting. I would retreat to the silence and actually enjoy not hearing, or choosing not to listen, to the often-cruel comments in life. I would focus more on the sweet sounds of music and nature that I could still enjoy. Surely this was a learned and unconscious coping mechanism that sustained me through this time.

While my classmates were learning French or Spanish, I was a self-taught student in speech reading and reading body language. I remember all through school wondering what the teachers were saying as they turned toward the blackboard to write numbers or words. Math was particularly difficult, as the teachers would face the board constantly while writing. They must have been giving instructions that I never heard. All these years, I thought I was incapable when it came to math. If one does not know what they are missing, they cannot ask questions to clarify. English was my talent because it was almost all reading. I did not have to hear to read!

It was not until I was 29 years old that I had a full hearing evaluation and began the road to acceptance and adaptation as an adult. My hearing loss was only one of my disability experiences as an adult.

At age 36, my vision suddenly diminished. My peripheral vision and patches

throughout the entire field of vision were affected. Thinking it was my contact lenses I went to an optometrist. He did a thorough exam, including a field vision test. He explained to me that he suspected a series of strokes were occurring. He had already made an appointment the next day in downtown Seattle, where we lived at the time, with a well-respected neurologist. This physician insisting my husband be present at the appointment made the seriousness of the potential problem more valid. I thought strokes were only an occurrence in the elderly and felt he must be incorrect. But I grew more concerned with his urgency in having me see this neurologist. Especially since he made the appointment and *then* talked to me about it.

The neurologist did a thorough neurological exam, ordered a CAT Scan and instructed me on how to watch for symptoms. He agreed with the other physician that a series of strokes was a possibility. I saw him frequently between June and November. By December, many things were happening - lack of balance, low vision, double vision, slurred speech, tingling and spasticity of my limbs, eye pain and numbness in various parts of my body. I called the doctor terrified and he saw me the next day. These physicians made exceptions to eliminate my fearful reactions.

He had ordered a MRI (Magnetic Resonance Imagery.) He immediately read the MRI results and then we studied the films together. He concluded I had Multiple Sclerosis (MS.) My initial reaction was almost relief. Knowing nothing about MS, somehow it sounded "softer" than a series of strokes. Time has taught me that the two are quite similar and taking care of one's body in all aspects is the best way to manage any health problem. This entire series of events took me by complete surprise when it all started thinking my contacts were defective.

The neurologist began counseling and educating me in ways to learn about MS and how to care for myself. He gave me a book to read and referred me to two cookbooks for "heart healthy" cooking. I felt I had some control over the symptoms once I learned more about a healthy way of living. That included physical, emotional and spiritual living. I believe the three are connected.

As I learned to cope with decreased control of my body and the fact that MS is not predictable, my ability to hear continued to decline. I bought a hearing aid three years after my MS diagnosis and 10 years after I knew I needed at least one. My world of listening began to open up for me.

One evening tears streamed down my face as I listened to the cicada chirping on a warm, autumn night. I had not heard these sounds since childhood, on my grandmother's farm. The autumn night fragrances, the stars peering down and the sounds all surrounded me, comforting me. The tears were a reaction of pure joy of a memory that had been tucked away.

Communication improved and I did not feel as isolated during most conversations. As time passed though, my ability to hear continued to change from a moderate hearing loss to profound deafness. Acceptance and adaptation was difficult. Having been a musician - singing, playing the guitar and writing music - I had to let the music go along with my hearing. It was like saying goodbye to a lifelong friend.

My family, friends and I learned to speak only when we were facing each other, the telephone became nearly impossible for communication, and the use of e-mail was not common as yet so we all had to be creative. We wrote more letters and notes and when together, my grown children would repeat what they had told my husband on the phone. Visits were more frequent but large family gatherings were torture for communication.

Some people, other than my immediate family, still denying my hearing loss, would shout when I asked them to repeat or wave me off frustrated that I could not understand. I had to advocate continually by teaching communication skills. I learned to say things like, "Could we go in the other room where it is quieter?" or "Would you just tell me what topic is being discussed?" People eventually learned how to be effective or simply refused to communicate. Some people I thought were friends, literally faded from my life. Either it was too much work for them or maybe they weren't friends to begin with.

Once I accepted my deafness as part of who I am, then my family and friends could do the same. I learned American Sign Language, began using a TTY (Text Telephone) and the relay service, honed in on my learned skills of reading lips and body language and began to

advocate for others and myself. I built on what self-esteem I had remaining to begin the slow process of becoming a whole person without much hearing plus an undetermined future physically due to MS.

Reading lips is not an easy skill for anyone to learn. Since I started learning as a child, it became natural for me, an aid in understanding the spoken word. When MS affects my vision or level of concentration due to fatigue, lip reading is exhausting and tedious. Even an expert in reading lips can understand less than 40% of what is being spoken meaning that potentially 60% of conversation is lost. There is a misconception that the deaf or hard of hearing people naturally learn to read lips. Some never acquire this skill. Lipreading with a vision problem or in dark environments adds to an already challenging situation.

My TTY is a tremendous tool for keeping connected to the hearing and deaf worlds. If the person I am calling has a TTY, we type back and forth using the codes GA (Go Ahead) and SK (Stop Keying) to designate the other person can type now or that we are done with the conversation. It is a remarkable apparatus. If the person one is calling does not have a TTY, the call is transmitted through a relay service. The caller dials a 1-800 number and asks the relay operator to place a call for them. Often when a hearing person receives a relay call, they think it is a telemarketing call and will hang up. This happens when the operator identifies they are calling from a telephone company before naming the actual deaf caller. This is frustrating for all parties involved.

Once connected, the person relays their verbal message to the operator, the operator types everything said (including background noise) and the deaf person types back to the operator and the operator verbalizes it to the hearing person. It is time consuming and many hearing people dislike a third party involved in the conversation. What I hope people will do is look past that uncomfortable feeling and simply communicate the only way I can on a telephone.

Deafness and most MS symptoms, i.e., numbness, muscle spasms, fatigue and depression, are invisible. Developing my own style of informing others that I am deaf or have limitations physically, has taken time and practice. I keep an attitude of understanding they cannot see my needs. A smile is usually present when talking or informing others. I am very slow going down the stairs and I use extreme care. To increase comfort of those around me during fire drills or on a campus with many younger people whizzing by me, I often say "I am in the slow lane. You can pass me with no problem!" Laughter inevitably follows. Everyone moves at their own pace.

If someone asks if I need assistance, I simply state I am slow due to MS. Sometimes this leads to a discussion. My deafness then plays a role, as I can't really talk in a "sideways" conversation. I must be facing people to communicate. So if people continue a conversation, I must then state I am also deaf and need to wait until I reach the base of the stairs to talk. My speech being clear, this confuses people. Since both deafness and the MS are invisible to the onlooker, my credibility is sometimes questioned. But I continue to smile and show patience, hoping for the same in return.

My husband and I have developed a private sign language. My grown children know enough to fill in the blanks and my youngest daughter is teaching her children sign language and extended etiquette. "I always want my children to be able to communicate with their Nana!" my daughter stated. I first learned sign language in classes a local Deaf Services Center offered to the hearing community. Learning ASL is not easy but it can be fun. I am outgoing but learning to express myself non-verbally was a real challenge. ASL consists of a tremendous amount of body language and facial expression. Learning the hand shapes, proper eyebrow movement to denote a yes/no question or a more detailed question, good facial expression and the actual signs is complicated. It took several years to feel comfortable using this language. Plus, I was living in the hearing world where very few people use sign language. Learning Spanish might be easier because of the availability of Spanish speakers and Spanish language television programs.

I had to be a self-advocate and delve into Deaf Culture and see if I would be accepted, see if I would fit. I attended a church for the Deaf for a year, befriended some people that were born Deaf and learned that an effort to communicate was the key, not so much how well it was done.

A severe episode of my MS, about seven years ago, caused my right hand and arm to become desensitized and partially numb. This makes finger spelling (hand shapes designating letters of the alphabet) very difficult.

I learned that many culturally Deaf did not learn ASL until their adult years, much the same as myself. They were raised oral or speaking. Imagine having to learn to speak never hearing sounds or your own voice. This fact helped erase some of my fears. I continue to seek opportunities to use ASL and learn of the Deaf Culture, which runs very rich and deep.

My feelings of isolation continued to diminish. I am now a student at a local community college known throughout the state for their strong ASL/Interpreter's program. My base in ASL is strong and now I am refining my skills. I want ASL to be as natural as speaking. It will take time but I am motivated.

My husband, children and close friends never allow me to take myself too seriously. I never lost my sense of humor. But they never downplay the effect that my physical losses have on me, as a person. It seems most people know someone with MS. Some people, when I was first diagnosed, with MS, would tell me of these others with MS. Saying they use a wheelchair, or can't walk or in some way were overcoming so much more than I was. They would say that I should count myself lucky.

I think those saying these words to me are denying I have MS because I am "doing better" than my peers with MS. I feel they are almost disappointed that I am not using a wheelchair. This saddened me because there is always the possibility that I could require a wheelchair. I was, and am, living with recurring-remitting MS as the course of my disease. This could change at any time. Is it a contest? This philosophy is foreign to me. I continue to meet similar reactions throughout all of society. "You have MS? You look normal. You're deaf? You don't look like you have MS and you talk fine, you can't be deaf." Rather than choosing to continually prove these facts to everyone, I determined to be selective with whom I tell and the mode of communication I use.

To advocate strongly, using personal experience, two years ago I began a column in the local paper regarding deafness, hearing loss and recently MS and other disabilities. I prefer "special" abilities for verbiage. I write on topics related to improving how society views people in general. My desire is to offer ways for others to see the person first, no matter a person's situation. Many conditions are invisible and must be made visible.

I believe the majority of people want to help and understand others but may not have the opportunity to show they care. Many people may not know how to assist people who seem to need assistance. Disability, special needs or having too many bags, people often appear to need help and good intended people like to oblige.

Opportunities for me to do public speaking have evolved as a result of my writing. Several talks were directed at school teachers. I urged them to learn how to recognize when a child has a hearing loss. I encouraged them to act on their discoveries and not keep it secret worrying they might be incorrect. It is easy to think a child is not paying attention when, in fact, they cannot hear. Speaking from a personal perspective made an impact. My old experiences of feeling alone afford me these opportunities to speak from the heart.

Depression, common with MS, reared its ugly head in December 1998. Waves of sadness would engulf me, appetite was minimal, sleep was elusive and I was irritable continually. Sleep deprivation and lack of appetite increased my MS symptoms, especially fatigue and cognitive functions. My doctor recognized these symptoms and is treating the depression successfully.

At the same time, I sought counseling. The counselor walked me through the painful valley of releasing suppressed pain. We gave a name to the pain, treated it and bandaged the wounds. Now I could heal completely. No matter what people did to me in the past or might do in the times to come, I could move on as myself. After many years, this was a comforting revelation.

No longer are societal standards important to me. I speak with passion and compassion, dress comfortably, spend time with my husband, grown children and grandchildren, write from the heart, sleep deeply and dream sweetly, accept others as they are and am less concerned each day about others accepting me.

It was interesting for me to learn that depression is physical. My MS exacerbated chemical imbalance that causes depression. When my doctor explained this to me, I realized I had an incorrect knowledge of depression my entire life. I thought that depressed people were sad people, not that their depression was a physical response. When I realized that many of the symptoms of depression I was experiencing were completely physical, that confirmed this new knowledge. It is treatable and manageable. I was not reacting to my life circumstances, my body was crying out for balance.

My deafness, MS and depression define, in part, who I am. Life experience opened my eyes to life, as it could be, all the possibilities. Hermann Hesse states my thoughts beautifully in the following: "It is not our purpose to become each other; it is to recognize each other, to learn to see the other and honor him (sic) for what he (sic) is."

If we struggle to please every person we meet, our days will end with frustrated exhaustion. If we live true to ourselves and express integrity, honesty and compassion, we may still be exhausted at the end of the day but an exhaustion that simply allows us to recount the small victories and rest knowing we did our best. That is all that can be expected from each person. To live our lives the best we can. In that manner, adulthood need not be an unsolvable riddle. Adulthood then becomes a time of fulfillment where our life is an open book and our story is interesting in the fact we have no secrets and no hidden agendas. We are moving on as unique individuals who have learned to cope with what life hands us. We are finding our way on life's path with a spirit willing to take risks and grow.