Is “person-first language” personal? Navigating linguistic prescriptions in EA counselling

Yvonne Oetter

Existential Analysis Society of Canada

Author Note

88

Table of Contents

Abstract

“Person-first” language is a type of linguistic prescription that refers to what a person *has* (e.g., a person with schizophrenia) rather than to who a person *is* (e.g., a schizophrenic). The idea of person-first language was first introduced in the late 1950’s in hopes in hopes of changing society’s perception of disability; to negate discrimination and increase inclusivity. That said, however, some questions persist about the “correctness” of person-first language: a) is it appropriate for all differences, b) does it protect the dignity of a person or perpetuate stigma, and c) is this language for the people with differences or for the people perceiving them? The field of disability research has revealed that “identity-first language” is actually preferred by many disability groups as it does not attempt to separate the person from their disability. This separation can imply the person is flawed (I.e., blind, deaf and autistic person) and ignores that some may have actually integrated their difference as part of their identity. In Existential Analysis (EA), we describe the person as undetermined and undefinable. A person is pure possibility, unique and irreducible. Thus, it makes sense that we try to adapt our language in a way that does justice to address the *person*. Drawing on EA principles, this paper will advocate for an attitude of phenomenological openness when working with people who have physical or mental differences, and to be aware of our assumptions that the person would like their diagnosis to be secondary rather than integrated. As a blind person and EA trained psychotherapist myself, I will share my personal and professional experience on this topic in hopes of initiating dialogue on an issue that is largely unchallenged outside of disability arenas.

Keywords, : Existential Analysis; phenomenology, person-first language, politically correct language, disability, blind, Existential psychotherapy.6

I was standing in the vicinity of the service counter at my local grocery store. “Hello?” I called out, hoping someone would look up and see me standing there with my white cane. “Can I help you?” A woman answered. I replied, “Yes, could you please help me pick up a few items…I’m blind.” The woman strode quickly towards me, and playfully said, “You are not blind. You are a person with a sight limitation.” She nudged me with her elbow to indicate that I should grab on, and asked me which items I was needing that day. I knew her “person-first” comment was the most current, politically correct terminology for someone like me, and in her perception perhaps a way to show her sensitivity and kindness. At the very least, she certainly meant no harm. Then why did it not sit right with me? There was something about this short exchange that was off-putting but I could not put my finger on it. If you had asked me at the time, I might have said I felt offended; but at what? I could not answer that. It was not until I completed my training in Existential Psychotherapy that I was able to understand this feeling more fully, and my “offence” had more to do with my wanting to be seen and accepted as is; no modifications necessary. Person-first language was designed to preserve the dignity of the person, yet it somehow falls short.

Person-first language is a linguistic prescription that attempt to tackle the very complex issue of categorizing a person’s difference. It fails to consider differences in terms of impact on the person, onset, severity, a person’s environment, how they are dealing with it and how is it visible. Despite these and many other variables, publication guidelines provided by governments in Canada and the United States state that all publications must use person-first language. Even within this prescription, the language continues to change. For example, I used to be called a person with vision loss, a person with sight limitations, a partially sighted person, and now the most current is person with sight loss. I wonder if a person born blind can lose something they never had? Language continues to evolve as we try as a society to come closer to a just way of describing a person who falls outside the mean average on the bell curve. For example, I use the terms “differences” and “disabilities” interchangeably for flow rather than correctness. The term “differences” is not yet in the guidelines, but it is something I am hearing more and more in media. You can look up the appropriate terminology to use for any given group, but many would argue that it is outdated. This observation is my own and that of the community of blind people I belong to locally here in Vancouver, BC. I will argue that as clinicians, we should be careful about blindly accepting the current, politically correct term when encountering our clients. I believe that the language a person prefers, either person-first or identity-first, has more to do with how prominent their disability is in how they can be in the world and how integrated it is in their identity. Does their disability change how they live their life in a way that it cannot be denied? For example, does someone who has occasionally epileptic seizures have need the same degree of integration as someone who is profoundly deaf? Furthermore, do we expect that someone who becomes blind in adulthood have the same experience and identity integration as the one that was born blind. The complexity of the issue and the inter-disciplinary requirements are beyond the scope of this paper. What I can offer is my own personal experience, as I moved through the various stages of ability and how I dealt with it personally. I will use the principles that I learned in my Existential Analysis (EA) training as the framework in understanding this journey. I hope this contribution will add to the discourse surrounding the language we use when talking about and with people with differences.

To Capture the Essence: Evolution of Linguistic Prescriptions

“Words are but the vague shadows of the volumes we mean. Little audible links,, they are, chaining together great inaudible feelings and purposes.” – Theodore Dreiser

The idea of person-first language is documented to have began in the late 1950’s as advocacy groups and speech-language pathologists initiated a movement that searched for ways to speak about people belonging to specific groups in ways that preserved the dignity of the person, reducing the marginalization of these groups (Dunn & Andrews, 2015). This shift is referred to as the Social Model of viewing disability and considered an improvement from the earlier Medical Model and before that, the Moral Model (see Dunn & Andrews, 2015 for more information on these models). At it’s core, person-first language seeks to acknowledge the “inherent and equal value of every individual” before attaching any other descriptions; a concept pioneered by social psychologist Beatrice A. Wright (1983). Over the years, researchers contributed increasing evidence that person-first language does indeed shape the perceptions of those observing such groups. As a result, governments and organizations have adopted the recommendations of this movement, and have implemented guidelines on how to talk about, write about, and present in images or media, using person-first language. At the highest levels of government, down to the individual therapist writing case notes, policies tell us to use person-first language. Since 1988, when it first appeared in government documents, we changed the culture in how we speak about specific groups and stands as “correct” today.

As our society continues to shift in its efforts to better adequately use language, disability research and disability groups have responded to the use of person-first language as inadequate and even harmful, having the opposite effect of its original intention. This newer model of viewing disability is referred to as the minority or diversity model, which suggests that disability is a neutral, natural and or even positive characteristic of a person. Advocates and authors of this camp make reference to the old slogan from 16th century Europe, “Nothing about us, without us.” In other words, if a policy is to be developed that concerns us, we should be the major contributor to that policy’s development. Proponents of identity-first language believe that the thing that makes them different, is nothing to be ashamed of. So as with person-first language, identity-first language also has the aim of preserving the dignity of the person. Some disability groups, specifically the blind, deaf and autistic communities, publicly denounce the use of person-first language and promote the use of identity-first language when speaking about it’s members.

I have also been shaped, perhaps implicitly by the Social Model of disability. I learned to view people with disabilities as people first, of course, with an unmentionable piece to them that I should avoid at all costs. I mostly came to this view through watching how others behaved. As children, we observe differences and want to ask questions, only to be quickly shushed. I learned this was how to be respectful around someone...you know, someone who was different. As I gathered information for this paper, I realized how prominent the Social Model of disability still is. For instance, a website for Educators (edutopia.org), it credits person-first language as having a profound impact on students sense of inclusion in the classroom, and encourages continued use as if it were as indisputable as gravity. Further, in the Government of Canada publication, *A Way with Words and Images* (2013), it says “People with disabilities are asking Canadians, and media in particular, to use respectful terms when writing and speaking about them” (Retrieved from canada.ca). It says that words are precise and not interchangeable and that all descriptors should be adjectives and not nouns. The example they give is “super-achiever” being an inappropriate noun to describe a person as it is judgemental. How then, should one call a mother, a doctor, or a client without using nouns? The authors referenced a long list of disability organizations that were consulted for this publications. I have to question if members of these groups were consulted or if the groups’ representatives were consulted. I ask this because according to the National Federation for the Blind (NFB) a disability group in the United States and one that predominates the landscape even here in Canada, purport that person-first language perpetuates the implication of shame instead of true equality (NFB, 1993. P.1). This publication is 20 years older than the Government of Canada’s publication. As a person who identifies with the visually impaired community, I do have a preference for identity-first language today, but I did not always feel this way.

Identity-first language is considered to be of the minority or diversity model of viewing disability which is the most current of models. As a society, we have viewed disability through the moral, then medical, then social models. The minority model views differences as a valued or celebrated part of identity (Brueggemann, 2013). It views disability as a culture, much like other oppressed groups such as race, religion, gender, sexual orientation, ability, class, etc). Disability is viewed as a continuation of being and not a deviance. Yet still, the American Psychological Association’s *Publication Manual* (APA, 2010) has not been updated to reflect this movement, and still mandates that all publications use person-first language. Outside of psychology literature (and outside North America), there is a growing movement within disability groups that are questioning the all-encompassing and universal use of person-first language. Instead they are promoting the use of identity-first language, with the assertion that disability is not a state of “bodily impairment, inadequacy, failing misfortune...that it is not about marking things gone ‘wrong’ with the body.” It can be viewed as a shared narrative composed by the specific disability culture (Brueggemann, 2013). Activists and scholars in disability research suggest that this approach allows a member of a particular disability group to “claim” as their own and having the choice as to how to be referenced (not having others choose for them). That said, however, there are few studies that actually measure the language preferences of members from these groups.

Does a person with a disability automatically arrive at this point when there is acute onset in adulthood? Dunn and Andrews (2015) suggest that the extent to which an individual adopts identity-first language may depend on the stage of identity development in terms of their disability, adding that this area has not received any empirical research to date. Integration of disability into identity development is a process that happens over time in ongoing dialogical exchanges between the person and the world they live in. Therefore, it would seem more appropriate to understand and utilize each model in clinical practice rather than to insist on prescription that only one or the other should apply. Consider adapting to a new job, or a new part of the world. It takes time to say, “I belong here”, and to prescribe a label to someone before they are ready, or have matured beyond person-first language, may lead to some awkwardness. It is from my personal observations from the perspective of a clinician and a person with later onset disability that I try to bring awareness to the complexity of this topic.

Development of Disability Identity Through the 4 FM’s

“To be human is to be questioned by life, to live is to give answers.” - Viktor Franklu

I became a student to the school of Existential Psychotherapy in 2014 and continue to work as a clinician through this lens as well as live my life based on its tenets. Existential Analysis can be defined as a phenomenological and person-cantered psychotherapy with the aim of guiding the person to a free experience of their mental and emotional life, to make authentic decisions and to discover a truly responsible way of dealing with life and the world (Längle, 1993). The inception of Existential Analysis (EA) began with Victor Frankl and further developed by close friend and colleague, Alfied Längle. In EA, the human being is understood not in terms of drives, but holistically as part of a larger context and of being innately free, even if only free to choose one’s attitudes. It is in this freedom that we can learn how to deal with ourselves in this world. To carry through life that unique inner-most person that detects what is truly important, and to include in when responding to the challenges of life. It is the spiritual part of us can laugh at a joke, long for something never possessed, and to experience awe.

Between 1982 and 1992, Längle created a structural model that helps us understand what moves us as human beings. This model connects human existence with 4 key areas in which we all strive for fulfillment. These areas are; 1) being in the world, 2) relationship to life, 3) being oneself and, 4) towards a future and meaning. As human beings, we find ourselves in constant dialogue with these 4 “fundamental motivations” (FMs), and fulfillment occurs when we can find and give an answer; to give an inner “yes” to these 4 questions of existence. This brief description of Existential Analysis will be expanded on as I use the framework to explain my experience with vision loss and the simultaneous change in how I view disability in myself and in others.

I always knew that there was something wrong with my eyes. I used to think my pupils were faulty as I always struggled to adjust to dim lighting and I could barely detect stars in the sky out of the corners of my eyes. I had a hard time finding things. I dreaded when my mom sent me to the basement to grab something as it would take me a really long time, annoying my mother. As I got older, it was just known that I could not see as well as others. I was clumsy, and I lost things very easily. I would bring it up to my optometrist, who would remind me that I had strong astigmatism and not everyone can have perfect vision. It was not until another optometrist examined me and noticed a silver sheen on my retina. I was referred to a specialist who told my I had retinitis pigmentosa. I did not know what this meant. He told me to stay focussed on the tip of his nose while he moved his hand in front of his face and then slowly away from his face. “My hand should disappear right about here,” he said. His hand literally vanished as he said it and I became confused and alarmed. The specialist explained to me that my retina was deteriorating from the periphery. He recommended that I register with the Canadian National Institute for the Blind and book a follow-up appointment in about a year. I had no intention of doing either of those things.

I oscillated between bouts of alarm and denial in those first weeks. I did not know what retinitis pigmentosa (RP) was, nor did I really want to. It took some time before I found the courage to learn what it was. In 1995 the internet was fairly new but there was one site that described RP as a genetic, degenerative eye disease by which the retina slowly deteriorates from peripheral to central vision eventually leading to total blindness. It is the leading cause of blindness in people under 65. There is no known cure. I was 25 years old with my whole life ahead of me.

1st Fundamental Motivation (FM1)

I am here, but can I be? Do I have the necessary space, protection and support to say yes” to the world? Can I endure and accept the capacities and limitations of my being in this world?”

Those first months after my diagnosis felt disconnected. I was not sure how to reestablish my connection to my world even though theoretically, nothing had changed. I started to become preoccupied with locating my blind spots, alternating between denying the prognosis and life will be fine to doubting that life would be worth living as a blind person. I did register with the CNIB, completed orientation and mobility training, and received my first white cane. This cane was kept folded in the closet until I absolutely could not leave the house without it (about another 10 years). This is the fate of many white canes according to my comrades. Eventually, the idea of going blind faded into the background as was clearly not going to happen anytime soon. I can do this.

According to EA, in order to say "yes" I can be in this world under the circumstances given, we need to have a good perception of reality and then endure and accept *what is*. For this we needs to have 3 things; protection, space and support. Endurance means to have enough strength to persist in spite of what is difficult. Acceptance is to be ready to stop opposing that which is difficult and to develop a new relationship with, or a new attitude towards this reality. In other words, endurance is to stand at the precipice of the entrance, and to accept is to go inside. At about the 10 year mark after my diagnosis, I was *enduring* my increasingly narrowing life. It was not until I faced my first, real confrontation with the abyss that I crossed the threshold into *acceptance.*

I have had several "learning opportunities" as I adjusted to my vision loss, but none so attitude changing as the one I am about to share. As I had mentioned, the decline in my vision was happening very slowly, one retinal cell at a time, an imperceptible decline until I needed it and it was not there. It slipped away while I was sleeping. I cannot speak for others, but for me, my brain struggled "seeing nothing" and tended to "fill in the blanks". I did not know what I was not seeing until I tried to look for it and could not find it. Back to the experience that took me from endurance to acceptance. One afternoon, I was at a hair appointment at a local salon that was located about a 7 minute walk from my home. The appointment ran long, and I was surprised to see that the sun had gone down in the meantime. I had been planning my activities around good lighting for some time now and had just recently started carrying my folding white cane with me just in case. I felt confident that I could make the short and familiar trek home through a catwalk, left at the side street and down the hill and then right onto my street. I had made it half way down the hill when it unexpectedly reversed it's grade to uphill. I stopped in my tracks. I traced through my head where I could possibly have made a wrong turn, and more importantly, how do I get home. I thought I would backtrack until I found a familiar landmark. I listened for traffic and oriented to that. I figured I had to be in an area behind my house, an area that was full of cul-de-sacs (dead ends). Car headlights approached me and I waved my arm wildly but they did not stop. I was beginning to feel the onset of panic. Should I scream for help? This was becoming plan A as I started to live out the possibilities in my imagination. Trying to find a front door of an unfamiliar house did not sound like a g ` ood idea. My lurking about could very easily be misinterpreted. Although, perhaps the police would be called. This was a definite plan B. I thought about all of my options, none of them really appealing and then asked myself, what if I’m lost here forever and disappear? Get kidnapped? I played it all out in my imagination. Realistically, I was in a tightly packed residential neighborhood. A kidnapping would be unlikely as there would be so many witnesses. I would put up a massive fight. I soon came to the conclusion that the absolute worst thing that could realistically happen would be that I would have to wait until the sun came up the next morning. Not ideal, but I could survive it. As I contemplated strategies, and arriving at an endurable possiblity, I experienced a growing calmness. I could feel the ground underneath my feet. I was in my own, safe neighbourhood albeit lost. In this moment, I heard a glorious sound, “Roxy!”. A woman was calling for her pet. “Hello!” I hollered, “I need your help please, I’m lost!”. My voice shook as I tried not to sound too desperate. The woman apologized that she could not help me as she did not have a car. I asked her if she could just verbally orient me to the area. She said she could walk me home but she would have to change out of her pyjamas (was it that late?). I considered this offer for a moment but felt a sudden wave of confidence. I politely declined and asked if she could instead help me draw a mental map as I knew I was close to home. This “map” would also help me for next time. She described the area and the streets, and while keeping the sound of the main drag north of me, I managed to make it home. I felt like I had been gone for months. I also felt stronger.

I was faced with the fundamental question of “can I?” Having adequate protection, space and support are prerequisites for saying “yes” to being in the world. These were available to me in this moment and generally in many moment leading up to it. I grew up with, and continue to experience environments that offer protection and support, with enough space to grow as a person and develop competencies. This started with my family. I grew up with this feeling of trusting in the world, myself and others that was never shaken out of me by an overwhelming situation. I connected with the blind community, forming invaluable formal and informal supports. Getting lost was a common, shared experience that we can giggle about with each other whereas others might be horrified. It has simply become a part of our lives, and not once have I heard of anyone being harmed. I had been initiated and felt some pride. The blind community demonstrated the possibility of living just as good a life as anyone else I knew; in fact, maybe even fuller and more intentional. This group seemed to be more grounded in reality in their limitations which were fully acknowledged and worked around. I had organizations that supported my skill development and even assisted me in returning to school to complete my bachelor’s degree. Through this, I found the confidence in practicing, building on old skills and being open to learning a new way of being in the world.

2nd Fundamental Motivation (FM2)

I am here, but do I like to live this life? Do I experience time, closeness and relationship to good things? Do I turn towards my values and losses and allow myself to be moved/touched? Do I say yes” to life?

I was an emotional child. Always just beneath the surface were tears ready to spring whether they were evoked by joy, sadness, fear or disappointment. I was teased about my “crocodile tears”. It took me decades to get a handle on them; not that I minded them so much, but I knew they bothered others, or so I thought. By the time I received my RP diagnosis, I was quite skilled at tempering any strong feelings. At the time, I felt dignified in the stoic image I portrayed in dealing with the diagnosis. The eye disease did not take my sight immediately, so responding to the diagnosis was different than responding to the actual loss of sight, which turned out to be very slow, an endless series of micro losses that in and of themselves were not “big” enough to make a big deal about. It began in small increments, almost imperceptible; not being able to find things, minor accidents, clumsiness, broken dishes and numerous spills. Over time, my vision continued to deteriorate; indoors became too dim and outdoors too bright. Open cupboards and dishwashers became serious hazards, I could no longer shop independently, I was forever misplacing things that I just had in my hand. It was the most noticeable that my vision was declining, not on a daily basis, but when there were long gaps in between seeing something familiar.

I live in beautiful British Columbia, Canada, and the scenery throughout the Province is spectacular to say the least. I spent many a summer touring through it to a favourite camping spot or to visit friends and family. I loved to revisit my favourite spots and marvel at their majestic beauty. Over time, not only did I feel I could no longer fully experience these favourite spots, they started to become foreign and unfamiliar. I also noticed that previously familiar places and people lost their familiarity. I was unable to recognize family members and could no longer enjoy a movie or a TV program with them. I have many stories to share about mistaken identity that were mortifying at the time (funny to me now looking back). Life began to feel strange and I began to feel removed from it. I was still functioning at work and home, making adjustments over the years as I have always done. I noticed, though, that life had become muted for me. I struggled to feel it, and soon became preoccupied with this lifeless feeling. Over a matter of weeks, I began to lose my appetite and my energy was reserved only for necessary tasks. I was agitated and short with everyone and found myself loathing people as they talked about trivial things such as traffic or their appearance; 2 things I could no longer relate too. My depression deepened over the months and I could not shake it off. Food became a tasteless chore. People would try to cheer me up, and I found this very stressful as I was compelled to make them feel better for their efforts by acting cheery, but I could not feel it.

According to EA, to experience the value of life one needs time, closeness and relationship to things/people they value. To know what one values requires a good relationship with oneself. We need to turn towards ourselves, to give ourselves time and closeness to build that relationship. We need to pay attention to our “likes”, as well as to grieve what has been lost. In my effort to not feel the effects of my declining vision, I inadvertently cut off from myself. I had hit such a low point in my life that getting out of bed seemed pointless and I was struggling to keep food down. Antidepressants had not helped and I had the feeling that I would be perfectly fine with never waking up again. I could not live this way anymore.

It was the end of January and I had been asked to take care of a friend's animals while they were away. There was a horse and a dog that needed feeding, watering and walking over a long weekend. This is something I had done plenty of times in the past, but this time it felt completely overwhelming. The feeling had nothing to do with my level of vision and ability. I simply did not believe I had the energy or mental fortitude to be responsible for these 2 animals. I called on a friend to help me. They were initially perplexed until they heard in my shaky voice that I needed them, and not just to help with the animals. My friend arrived with his guitar, a deck of cards and a box of plain crackers. He put the the box of crackers in front of me and went into the kitchen and got me a glass of water. He did not instruct me to eat or drink and he did not ask me how I was feeling. He intuitively knew I could not bear the pressure and for the entire weekend, I felt like nothing was required of me and I did not feel guilty about it. He seemed to just know what needed to be done and did it. He played his guitar, making up random lyrics about the long winter and crocus starting to come up and and cinnamon buns. I did not get the feeling that he was trying to cheer me up, but played for his own amusement. These three days I came to the realization that I had not been very nurturing or compassionate with myself for some time. I had been pushing through with the stoic front because I thought it was the best approach for me and I thought it would be easier on others.

My friend's ability to accompany me that weekend was a catalyst. I could feel those familiar hot tears pushing up from a place I thought I had buried in the 90's. I had my first bonafide pity party, and it felt so good. I mostly grieved the loss of the life I had imagined for myself as a "normal, able-bodied person". I grieved the loss of being able to behold a spectacular view in nature and the familiarity of my family’s and friend’s faces. I did this in private as not to alarm anyone, but I did not feel isolated. I was there with myself. I could feel things moving in me again, like the crocus ’popping up after lying dormant in the frozen ground, as if from nothing. At the time, it did not seem sensible or helpful to cry so much and I was surprised how good it felt. During my training in EA, two phrases stood out that capture this experience perfectly; “Tears are the kiss of life,” and “tears of joy and tears of sorrow come from the same well.” Today, for me, my well is deep and full and I prefer it that way. I still try not to cry in inappropriate situations, but my relationship to my tears will not be broken by me again. I have learned to be touched by life through my other senses; through music, delicious food, bing in my body through movement and holding the people I love.

3rd Fundamental Motivation (FM3)

“*I am here, but am I allowed to be this way? Do I experience attention, appreciation and justice from others? Do I give these to myself? Can I encounter my unique essence and that of the others?*

My spontaneous response to this existential question is, “it depends”. If we are talking pre-diagnosis, I say “yes”. As to post-diagnosis, I say “no”. As to post-integration, I say “yes” again. In EA, developing as a person is an ongoing dialogical activity between the world (outer pole) and ourselves (inner pole). It is through this dialogue that we develop as a person, learning to take a position and act (as opposed to react) in accordance with oneself. It is a life-long process as we become more and more ourselves as we age. We grow into our authenticity and strengthen our authority. Attention, appreciation and justice that we receive from our caregivers is how our self-worth develops. Self-worth require a “dual mirror” reflective process as those around us reflect back to us who we are. We in turn, “digest” what is reflected back to us by giving ourselves attention, appreciation and justice. We “keep” what resonates, what is our own, and we discard the rest. In my situation, having been born sighted and then very, very slowly losing it, the “dual mirrors” reflection were from a funhouse; distorted and confusing for both me and the other.

The world reflected back to me while I was growing up was that I was a competitive, a good student, creative and adventurous. This fit how I saw myself and shaped how I wanted to live. I approached college with no real direction. I tried out a few different courses, loving the psychology and fine arts courses but being told that I couldn’t afford to be a psychologist because of student debt, or an artist as there would be no steady work. Nothing else really grabbing my interest so I took a break from college and picked up some odd jobs; one of which was at a pool hall. I became immersed in the sport, traveling the West Coast of North America competing and even winning the North American 8-ball Championship with my team. This tight community felt like a second family to me. They knew I had difficulties in dim light, but I could do well under the bright lights on the pool table. It was during this “hay day” that I received my diagnosis. I shared the news with a few people and as in all small communities, it did not take long for word to spread. Perhaps my perception, but it felt like people treated me differently afterwards. I remember conversations suddenly becoming awkward or avoided all together. We used to debrief a botched play in full to gleen ways to improve. Now, every shot I missed was a question of my ability, I felt like I was slipping away. Playing pool was never going to be a career choice, but it was my life at this given point in time. I think if I was doing something that did not require a sharp eye and did not involve performing and an audience, the impact of my diagnosis would not have been as dramatically felt. It was not that I was treated poorly, quite the opposite in fact. It was that I was treated like I was not me anymore. I do not care what anyone says, the "kid gloves" people used with me hurt.

I still had a lot of vision at this time in my life and could still do most everything I used to do. My peripheral vision was splotchy and I could not see well in dim light. So in my mind, I was still the same person. For others, the diagnosis explained a lot and therefore adopted a different way of dealing with me. Some people, who were previously annoyed with my clumsiness became overcompensatingly helpful. My offers to help other were often declined. Some people did not acknowledge me at all. For example, in restaurants, where lighting is dim and I cannot conceal my blindness, most servers will not ask me what I want to order, but will ask the person I'm with what I want. I remember another time around Christmas I was waiting outside a shopping centre for a tasi. A busker was performing one of my favourite songs. I turned towards the music, rested my chin on my cane and swayed to the strumming of his guitar. When he finished, I applauded, and feeling the spirit of the season, I told him I would like to give him $20 and if he could get it from me as I didn't want to guess where to put it. He politely declined and wished me a Merry Christmas. He perhaps thought he was doing a good deed, but what I felt in that moment was excluded. It reminded me of a vignette I read in Ryan Knighton's *Cockeyed: A Memoir* (2012) about his own experiences with losing his vision to RP. Ryan retells a story of when he was vacationing in New Orleans. He was walking back to his hotel in the dark when he realized he was being followed by 2 men. As he quickened his pace, they quickened theirs until they finally caught up to him. Upon seeing Ryan's white cane, the thugs apologized and turned away. Ryan was indignant that he was not even worth mugging. I could relate. Do we live in the same world as others or are we somehow exempt? Ir felt as though the more vision I lost the more invisible I became and there was nothing I could do to stop from vanishing.

I use taxis on a daily basis, and quite often would get the same driver. One driver in particular stood out amongst all the rest. He had asked me one day as he drove me to work if I had done something bad in my past. I said, “no” and enquired why he would ask such a thing. He explained to me that he believed that disability is a punishment for bad deeds and wondered what blindness might be a punishment for. His question was earnest and and I think he was hoping to avoid this punishment. I was not offended, but rather pleased to be of interest to someone who likely had picked me up many times before and to whom I paid no attention to. Of course the ride was too short to delve into a dialogue about the meaning of disability, but I was encouraged by the encounter. I asked the driver for his name and that we should continue our discussion next time he picks me up if he would be so kind as to announce himself. He agreed and said he would pray for me. It was not the prayer that I appreciated, it was his willingness to encounter me and a reminder that I could do the same back. He was my driver several times over the years, and we had a series of brief and always respectful discussions about blindness, being curious about the other’s position and always ending with me saying, “it’s not so bad...” and him saying, “I will pray for you”.

These types of encounters encouraged me to speak up more often, in a way that could educate people rather than have both of us fall into awkward silence or worse, superficial conversation. I had been the one to defer to my sighted fellow humans to take the lead because, well...they were able and I was disabled. This third fundamental motivation is fulfilled when I have the feeling that I am allowed to be the way that I am; that I receive attention, appreciation and justice from others, and just as importantly, I give these to myself. I realize now that it is actually my responsibility to let others know my experience because they are not mind-readers. Living a life with vision loss is different for sure, but it is not lacking by any stretch; and I have lived on both sides. I there something from my experience that could be meaningful to others?

4th Fundamental Motivation (FM4)

I am here, but for what purpose? Do I take part in a field of activity, that falls within a greater context? Does it offer the possibility that something good will come of it in the future? Am I oriented towards something beyond myself that is meaningful?

The 4th fundamental motivation is about being oriented towards possibilities, something fruitful to be realized in the future. This offers fulfillment through meaning. Meaning can be realized through creating something, new experiences and adopting healthy attitudes. Viktor Frankl in his best-selling book, *Man's Search for Meaning* (2000), speaks of the quest for *meaning* as being the primary motivator of human beings. This power resides in the unique essence of our person. Frankl says that suffering can be experienced as an opportunity to find meaning in life even when faced with a hopeless situation. Suffering can offer the opportunity to transform a personal tragedy into a triumph. Suffering often begs the question, “why?” We look to the universe for answers. Frankl suggests that we don’t look to life to give us answers, but it is we who are being questioned by life; daily and hourly. EA refers to this as the “existential turn”. Life ultimately means to give the best answers to life’s questions, and to fulfill the tasks that are constantly set before each of us, but the questions and answers we give are different for each of us.

After my diagnosis in 1995, I immediately returned to school to achieve something, anything; some sort of diploma that would generate more employment options. After very little contemplation, I opted for the quickest route to a diploma, and that was in business management.

It felt foul in my mouth to say it, but I felt it was my best chance at employment given the dark future I saw ahead of me. I did not know how quickly my vision would decline or how (if?) I could adapt. I got my diploma and landed a job as an office administrator for a small company close to my home. It paid the bills and I liked the environment. I passed as sighted when I was hired, but soon had to disclose my eye condition. My employer told me that I should have told him that before. I asked him if he would have hired me if I did. He did not answer me. I worked there for 13 years over which time my eyesight deteriorated and I was supported throughout. Accommodations were made and I was grateful to be working as most of my friends with vision loss were not working or were under-employed. As my vision declined I became more and more involved with the blind/partially sighted community. It started with formal supports through organizations for the blind from which developed many, valuable friendships and mentors; feeling stronger as I gained skills and confidence and began to feel at home in this new culture.

The financial crisis of 2008 hit our small company hard, and in 2011, I was forced to take a 50% cut in pay, or leave. I decided to leave thinking I would find another job in the industry I had worked in for the last 13 years. I was wrong. A few months later, my marriage ended. I applied for disability pension, but was denied because I had been working with my vision loss. When I was first diagnosed I used to imagine a bleak future as an old blind woman with creepy white eyes living in a one room apartment; the highlight of my life being a visit from a volunteers or grocery delivery. I was 42 now and those images crept back. I did not think that I could bear this future. I know it is a life that some people live, but is it ok with them to live this way? I guess you never really know what your capacities are until you get there. For me it was not a matter of being able to live under those conditions, I knew it was doable, but was it a life meaningful enough to be worth living?

Up until this time I had lead a very conservative life; always aware of the impending blindness and clinging to what was there in front of me and not entertaining the possibility of expanding my horizons. When a rehabilitation counsellor asked me what I used to dream about doing when I became an adult, I told her I wanted to be a psychologist, but that was impossible. She asked me if it was really impossible or did I just not want to put the effort in. She gave me a list of reasons why I should consider it and how it could be done. This woman planted a seed that rooted fast in an environment that I can only describe as divine intervention. Every door opened for me. The hodgepodge of courses I took 20 plus years ago were still valid towards a degree (no longer the case), the program that paid for my tuition was defunct after I made it through. The university I went to was a 5 minute commute from my home, and I had enough equity in my house to go all the way to completing my Master’s in Counselling Psychology 5 years later. I found work as a counsellor before I graduated in a field that required no accommodations. I am not a psychologist, and do not plan on pursuing a doctorate. I am fulfilled in my work and know I belong here.

Although I put a lot of effort into re-creating my life the last 10 years, the life I was living before losing my job was harder. It was a good enough life and I was grateful for it. However, I certainly would not have voluntarily opted to return to school and pursue a profession had I not had this “bad luck”. It was not until I was forced to seriously evaluate my life that I was able to imagine a different future. I was called in a different direction and I answered, but not out of fear as I had in the past. Viktor Frankl speaks about suffering as an opportunity to grow spiritually (2000). He says if something can be changed, you should change it, but to bear suffering could actually be considered an inner achievement that releases an inner, spiritual freedom that cannot be taken away. He goes on to say that a passive life forgoes this opportunity. I often wonder where would I be if I had not lost anything and lived a smooth easy life that I expected to live? I would not change a thing. I feel an openness towards the future that I had not felt prior to the job loss. My inner compass says I am moving in the right direction. I live this life fulfilled and with little fear. I have more to do, but I have already done a lot. I have camped in the Amazon, walked the Camino de Santiago, road tripped through Argentina and have appeared in a documentary and a television series. A relative asked me once if I was doing all of this activity to prove something. I told her that I was not concerned with how I appeared to others, but was feeling greedy for the experiences. I had come from a mindset that I would be a burden to to others because I am dependent on others. I wonder though if there is something that I can contribute; something maybe only I can give.

Connecting the Personal to the Prescription

I have lived with my declining vision for 27 years. Today, I have a small pinpoint of vision left in my right eye; enough to see high contrast, inverted text on my iPhone, but not enough vision to find my iPhone. I use a white cane full-time as I wait to get my second guide dog. I keep to familiar places unless accompanied by someone. I work full time as a therapist for a non-profit agency as well as do private practice. I have a very good life today. I feel a certain pride in having had gone through it. The reason I share my story is to personalize the topic of disability language in our work. To go back to the grocery store and the helpful clerk demonstrating her use of person-first language and my inability to identify the feeling I had towards the comment, I can say this. I have been raised in a society that sees disability as something unfavourable. I live in the same society that views overcoming adversity as inspirational. It is difficult to reconcile these two views in a way that does justice to both the difficulty of having a disability and feeling the deep pride of living well in spite of it, or even living better because of it.

As clinicians and writers, we could perhaps pause for a moment to consider what is really important here. Is the style of writing and referring to people with differences still valid and appropriate as it is? Could we, instead of automatically applying the linguistic prescription as required, look a little closer and allow the personal to emerge? What do you sense from the client? Shame? Pride? Neither because the difference has no impact on their life? Is their difference new to them or is it a major part of their being in the world? Only with a phenomenological openness towards the other, through dialogue and not prescription, will you find the person.

References

American Psychological Association. (2010). *Publication manual of the American Psychological Association* (6th ed.). Washington, DC: Author

Brueggemann, B.J. (2013). Disability studies/disability culture. In M.I. Wehmeyer (Ed.). *Oxford handbook of positive psychology and disband disability* pp. 278-299). New York, NY: New York: Oxford University Pressb

Dunn, S. Dana & Andrews, E. Erin (2015). Person-First and Identity-First Language: Developing Psychologists’ Cultural Competence Using Disability Language. *American Psychologist.* (Vol. 70. No. 3. 255-264).

Frankl, Viktor (2000). *Man’s Search for Meaning: An Introduction to Logotherapy.* New York: Pocket Books.

Knighton, Ryan (2012). *Cockeyed: A Memoir*. Vancouver: Crane Library at the University of British Columbia.

Lângle, Alfried (I1998) *The four fundamental conditions for fulfilled existence.* Collection of Writings by: Dr. Alfried Langle. Compiled by Dr. Leslee Brown Director Mond Body Passport Inc. book.

Government of Canada. A Way with Words and Images. Retrieved from https://www.canada.ca/en/employment-social-development/programs/disability/art/words-images.html#h3.8