

Editorial — Defining disability:

An auto-ethnography on the lived experiences of a person with cerebral palsy

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Abstract

The purpose of this auto-ethnography is to reveal how instrumental life situations for a person with a physical disability present opportunities to define disability, rather than allowing disability to define the individual. This paper explores the definitions of disability and impairment, and how locus of control can shape those definitions. Four theories are related to instrumental life situations and the desire to control one's disability: theory of reasoned action, self-categorization theory, developmental psychology, and dialogical self theory. The instrumental life situations and four theories are categorized by (1) Building Relationships and Acceptance; (2) Evolving Relationships; and (3) Defining Self. We categorize people by gender, race, ethnicity, and ability, amongst other things, particularly in regard to minorities. Once those categorical walls are constructed, they become difficult to shed. It is the consistent action of taking ownership in one's disability — or ability — that can make strides toward removing categorical perceptions.

I was born with cerebral palsy (CP), a condition in the brain that can affect balance, muscle spasticity, speech, and to a greater extent, cognitive abilities. My CP affects balance and muscle spasticity primarily, resulting in my use of forearm crutches for walking assistance. My gait includes bent legs and dragged feet. Seen at face value, it may not be the most pleasant of sights with stiff legs and quick movements. Others see me and may feel compassion and pity, or confusion and interest. They may wonder what I can and cannot do, and may assume or draw conclusions based on their own past experiences to explain why I walk the way I walk. In many eyes, I have a physical disability. Yet, disability cannot be explained or defined with some basic level of agreement among scholars, practitioners, and government agencies (Rothstein et al., 2002; Smart and Smart, 1997; Zola, 1993).

Face value often shapes the definition of disability. Crutches, wheelchairs, or prosthetics may be associated with disability and confinement that controls the individual. Yet, those innovative pieces of equipment are the very means by which a person with a physical impairment may use to enhance mobility, taking upon greater independence. I strive for others to see beyond face value by subduing my physical impairment into a secondary quality with the aim of allowing others to see me for who I am and what I can do rather than what I look like and what I cannot do. I strive for others to avoid making my physical

capabilities my only means of identification. It is not possible to completely disregard my physical traits, as my crutches are a marked characteristic of which I am not ashamed nor desire to hide. While physical characteristics may not be eliminated, my desire is for people to see other characteristics equally or with greater value than my physical impairment. I want to show that physical characteristics do not have to be the only means of identification by taking control of instrumental life situations such as participation in sport, shopping, or independently participating in social activities.

The purpose of this auto-ethnography is to reveal how instrumental life situations for a person with a physical disability present opportunities to define disability, rather than allowing disability to define the individual. I begin this paper by exploring the definitions of disability and impairment. The two terms are mistakenly used interchangeably, but are defined differently as set forth by the social model approach. Next, I explain locus of control and how it can shape perceptions of disability. I then apply four theories in relation to instrumental life situations. These instrumental life situations and four theories are categorized by the following themes: (1) Building Relationships and Acceptance; (2) Evolving Relationships; and (3) Defining Self. I conclude by discussing how my experiences may be applied by others. First is a discussion of auto-ethnography and the terminology used with regard to disability and impairment.

Auto-ethnography

Merriam (2009) defines ethnography as the study of human society and culture, with culture representing the “beliefs, values, and attitudes that structure the behavior patterns of a specific group of people” (p. 27). Auto-ethnography is a type of ethnography in which the researcher serves as the author while analyzing his or her own experiences as primary data (Ellis, 1993; McIlveen, 2008). Ethnography has its roots in anthropology, but auto-ethnography is connected with the practicality of therapy. Parry (1991) argues that writing one’s own stories is a way in which the author can analyze and interpret his or her own life. Introducing a third party interpreter creates the risk of losing the accurate interpretation. In fact, in the therapy setting, Parry (1991) states that there is “no better way to confuse and discredit a person in her own eyes than for someone else . . . to tell her what she is experiencing or what her experience means” (p. 5).

Based on this definition of auto-ethnography, there is power in providing emotion and cultural perspectives of one’s own experiences (Creswell, 2007). Ellis (1993) provides the best example of capturing emotion and perspective that may not have otherwise been accessible with her auto-ethnography on her brother’s unexpected death. In capturing the family’s experience with death, she sought to connect a lived experience with research to perhaps open the topic for greater discussion on academic and practical levels. It should be noted, however, that expressing those experiences is not easy. Auto-ethnography has

its challenges with regard to representation, objectivity, data quality, legitimacy, and ethics (Wall, 2008). Perhaps the greatest limitation is that auto-ethnography cannot generalize to a broader audience (McIlveen, 2008). Yet it may serve as a stimulus for discussion and study (Ellis, 1993; McIlveen, 2008; Wall, 2008). My goal is similar in that I aim to explore my own lived experiences with disability in a way that may create discussion of what disability means to others, and what it means to the person who lives with a disability.

Disability vs. Impairment

Disability is a term that gets used frequently without much thought of a proper definition. The Union of the Physically Impaired Against Segregation (1976) defines disability as the “disadvantage or restriction of activity caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities” (UPIAS, 1976, p. 14). Disability is a “situation, caused by social conditions, which requires for its elimination” (p. 3). The U.S. Census Bureau assesses disability through concepts of communication, mental, and physical disability as well as measuring activities of daily living, such as bathing and eating, and instrumental activities of daily living, such as leaving home or budgeting money (Brault, 2009). According to the U.S. Census Bureau, 36.1 million people (12.1%) in the U.S. population report having a disability (Brault, 2009). The term disability often is treated as synonymous with impairment, which UPIAS defines as “lacking part of or all of a limb, or having a defective limb, organ, or mechanism of the body” (p. 14). Impairment, then, refers to one’s medical condition, whereas disability is the social treatment one receives as a result of such impairment. This type of definition references the social model of disability, which removes medical analysis of disability and places emphasis on ability and any social constraints that prevent access (Grenier, 2011; Moola, Fusco, and Kirsh, 2011).

The World Health Organization’s (WHO) International Classification System of Functioning, Disability, and Health includes a discussion of impairments and acknowledges social influence on defining disability (WHO, n.d.). The WHO attempts to incorporate both medical and social analysis of disability, although the social model is widely accepted among the disability community. Still, adhering strictly to the social model to view disability is not universally popular because it ignores physical aspects of disability and other social divisions (Oliver, 2004). Imrie (1997, as cited in Brittain, 2004) argues that the social model assumes that changing the physical environment will result in changed experiences. However, it is not only the physical environment that dictates the experiences of a person with a disability, as psychological treatment can result in social isolation and oppression. Whether by physical or psychological oppression, the social model as defined by the UPIAS (1976) holds that it is “society which disables physically impaired people. Disability is

something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society” (p. 3). Disability, by this conclusion, is the result of society excluding people with impairments.

Based on the previous discussion, CP is my physical impairment. My disability is negative social treatment due to my physical impairment, such as exclusion from a second-floor restaurant that offers no elevator and no handrail with its stairs, as an example. To combat this oppression, individuals such as myself must “assume control over their own lives” and “professionals, experts, and others who seek to help must be committed to promoting such control by disabled people” (UPIAS, 1976, p. 3). Next, I will address how one can assume control over his or her own life.

Self-Reflection on Control

There are many factors in day-to-day life that cannot be controlled with a physical disability like CP. How tight will my muscles be when I get out of bed? How slick will the floor be because of the rain? Will my crutches slide on a stray leaf and result in a fall? Those thoughts consume my mind at times, although it is a positive sign that I am not choosing to remain locked indoors but rather choose to socialize despite the risks. Falling is rare, and few people know how to react aside from the natural panic attack. The way I cope is through laughter. Falling and laughing at the situation, assuming I am not broken in some capacity, instantly cures any panic that onlookers may exude. The laughter is a controlling factor, where I identify a situation in which I am not in control and take measures to obtain that control.

Locus of control is one’s own perception about the power source in life (Russell, 2009). External locus of control is when we perceive that we have no control and are merely pawns moved by forces outside of our realm (Russell, 2009). External locus of control is exemplified when an individual’s reasoning for not participating in physical activity is due to their disability or some constraint they perceive to prevent them from participating. Internal locus of control is when we perceive we are the origin of our own life events and is often connected to emotional maturity (Russell, 2009). Internal locus of control is exemplified when a person with a disability chooses to focus on what he or she can do despite the physical challenges that may be present.

Negotiation for locus of control can be seen as teenagers through relationship development that is largely dependent upon others (Russell, 2009). College is filled with pursuits of independence, while the adult years that follow include certain restrictions due to children or career patterns (Russell, 2009). The importance of locus of control in social recreation is enhanced for people with disabilities, particularly if they did not experience relationship development as a teenager, independence in college, or changes in independence due to adult commitments (Russell, 2009). For example, a person born with a physical disability

that experienced social isolation and was excluded from developing relationships as a teen may use adult social activities to reclaim internal locus of control. The challenge is whether the individual seizes those opportunities.

Establishing Trust

There are two types of people I encounter: those that ask about disability within the first few meetings, and those that never ask. My deep relationships include individuals who have done both. Students that I teach, however, exclusively have avoided the conversation, perhaps due to the authority between student and teacher. I often wonder what internal reactions are present when students see that their instructor uses crutches. I typically disclose my disability and talk extensively about it in class. The internal locus of control provides me great comfort in discussing disability with students by advancing relationships and proactively addressing questions they may have about my physical abilities or of my abilities as an instructor.

Conversely, it is gratifying just as it would be for any scholar when colleagues and students seek my advice on academic endeavors or career aspirations. However, as an individual with a disability, it covertly sends the message they are viewing qualities I possess aside from my physical traits. Those relationships often require development over time. When my relationships get to the position where the other person no longer offers to help me with the smallest of tasks — putting on my coat, standing up, or carrying my laptop bag — it confirms they have moved beyond identifying me first and foremost by my disability.

Relationship building in this instance aligns with the theory of reasoned action. The theory of reasoned action is based on the assumption that people are rational and make systematic use of information available to them (Ajzen and Fishbein, 1980; Belleau, Summers, Xu and Pinel, 2007). Based on this theory, people consider the implications of their actions before deciding to engage in a behavior. Applying the theory of reasoned action to the first day of class or when a colleague seeks academic consultation, the individuals are invested in a committed relationship and therefore may not wish to compromise that relationship. For example, a student in class who sees her instructor with crutches may not wish to risk damaging her status in the class by inquiring about the disability. Also, a colleague who asks a research-focused question may not have disability at the forefront of priorities, but simply may only wish to know an answer to his or her question. Alternatively, individuals have at times avoided asking me direct questions pertaining to disability, potentially due to perceived implications of the conversation. For example, colleagues have asked my academic mentor if placing a table blocking the automatic door opener to the office would affect me. Another colleague asked my mentor if a table was placed in the men's restroom at my request. In both examples, a potential explanation as to why the colleagues bypassed asking me the questions and instead asked my mentor may be their desire to

avoid an awkward social situation. One possibility is that those individuals perceived that implications of the conversation may damage established relationships, and that asking those questions would not be socially acceptable.

Social Acceptance

Experiences prior to my professional career include memories of influential instructors, social experiences, and play. I completed my seventh-grade requirement of running 15 laps around the basketball court in physical education class, finishing well after most of my classmates had changed into their regular school clothes. I finished the assignment to the applause from my classmates. My football talents were never questioned in the side lot of my church, playing with four other children of similar ages. An accepted rule in our make-believe games was any pass that touched my crutch meant I caught the football. In high school, I was permitted to leave five minutes early from every class to avoid the crowded hallways and was an active participant in social events. I played on the high school golf team, beating three golfers from opposing schools and receiving support from parents as I completed my matches at the 9th hole. Peers in college knew me from writing at the school newspaper and driving my car to classes rather than walking across the 560-acre set of buildings. Walking to class like the rest of the freshmen class was not ideal, and waiting on the university-provided shuttle van was not efficient. At age 18, it was the first time I regularly used accessible parking.

My social experiences as an adolescent and teenager can be associated with self-categorization theory (Turner, Oakes, Haslam and McGarty, 1994). As outlined by the theory, personal identity and social identity are distinguished as two levels of self-categorization. Personal identity includes self categories that define an individual as unique, highlighting the differences from others within the group (Turner et al., 1994). I often found myself as the only person with a physical disability in social settings such as sport events, social activities such as shopping, or classes. In fact, I did not have a class with another person who displayed a physical impairment until my second year of college so my personal identity was a person with a physical impairment surrounded by able-bodied individuals. Social identity, however, refers to social categorizations of self and others that highlight the shared similarities with others in the group (Turner et al., 1994). My social identity allowed me to fit in with other adolescents and teenagers, even college-aged young adults, because of my social involvement with teams, school-sponsored organizations, and peer groups. Connecting more with my social identity allowed me to perceive myself as part of a group, using “we” and “us” to identify with the golf team or a group of friends. Social identity, according to self-categorization theory, allows one to define self as part of the group (Turner et al., 1994). Shared social identity results in depersonalization of self-perception, allowing a person to see themselves as less different while identifying with a group of people.

I have been able to minimize my perceptions of my differences through creating a shared social identity and building relationships within these communities.

Evolving Relationships

Before my wife and I married, she left town for a weeklong vacation following our first date. It allowed me to spend hours on the phone with her and display my character to her rather than my physical attributes. I was able to display my inner qualities to her without the focus being on my physical characteristics. We quickly built a relationship from our conversations. Now, my wife holds me accountable for cleaning the bathroom at home, washing the dishes, and helping get our toddler son ready for bed each night, all typical physical expectations from a spouse. I never minded cleaning house because I quickly recognized in my early bachelorhood it was a series of physical tasks I could accomplish. Other household chores such as taking the trash down the steep driveway is not an easy task, but it is one I was forced to do the first week my wife travelled out of state. Thursday night, in the dark, can stuffed with trash in bags, I walked with my right crutch as balance and my left hand guiding the two-wheeled trash can down the hill while holding my left crutch horizontally. It was slow and not aesthetically pleasing, but the trash was in place for the following morning's pickup. Our 1940s-style house does not include a dishwasher, so my job in the kitchen increases when we dine in. I typically maneuver throughout our home with just one crutch as balance, so to wash dishes I lean it against the corner of the counter and brace myself against the sink. Caring for our son is a shared role, and my daily routine includes bathing him at night and helping him dress in the morning before going to daycare. These jobs may be regular chores for husbands, and I embrace having chores that are common among all households.

Prior to splitting chores as a married couple, my college roommate and I shared responsibility of maintaining our apartment. He and I were from the same hometown, graduated from the same high school within a year of each other, and lived together both on campus and in an off-campus apartment. Through living together, he quickly realized his role in physically helping me through life was nonexistent. I asked him for help carrying my laundry basket from my car up the eight steps to our apartment door, and I asked him to take out the trash. Conversely, I kept our apartment clean through weekly chores. I would say our arrangement in terms of physical requirements was equal. After living together six years, he once asked me to join him in a 5-kilometer race he was entering. Such an invitation confirmed he recognized the impairment but overlooked disability. In fact, others have casually asked if I am participating in events such as road races with our group of peers only to catch themselves, for a moment, forgetting disability.

Most of my relationships have evolved with the other person having to shift perceptions of my disability. My toddler son, however, has only known disability as part of our lives.

He thinks nothing of retrieving my crutches at 6 a.m. when he wants cereal and cartoons. “Papa, I’m hungry,” is quickly followed with him bringing both crutches to the side of the bed, leaning them on the mattress, and pulling my hand with a pleading cry. He moves at a slower speed with me as opposed to with my wife. He holds my wife’s hand when walking in a parking lot; he holds my left crutch when it is just the two of us. Three years prior, my nerves were shaky when faced with handling a baby, moving him from crib to living room, and holding him to feed him. After working with a physical therapist and practicing with heavy and awkward objects such as weights and plates of food, I mastered the art of carrying a newborn 100 feet from his crib to the recliner using just one hand and one crutch. I could have dropped him in what would have surely been a target of parental criticism. Yet without attempting to even achieve such a task at my own pace and using my own creativity, I would have been left without the full fatherhood feeling of physically contributing as my infant grew into a mobile toddler. I would have felt helpless in the task of physically caring for my son. My impairment would have transformed into a disability. In doing so, I would have succumbed to allowing the disability to define me. As a toddler, my son asks questions about why I have crutches and he occasionally questions my impairment, although it does not appear that he sees disability preventing me from an active lifestyle.

Using developmental psychology’s stages of development as a framework, the evolution of relationships relates to the theory’s early adulthood stage (Rogoff, 2003). It was during early adulthood when relationships with my college roommate, my wife, and my son evolved. It is during this stage when intimate relationships are formed with friends and mates. Establishing these relationships may be difficult if previous stages are not resolved, resulting in potential isolation, fear of commitment, and an inability to depend upon others (Rogoff, 2003). I was able to avoid isolation through establishing early adulthood relationships that prevented fear of commitment (e.g., I married and had a child with my wife) and an inability to depend upon others (e.g., I relied upon my roommate for actions such as carrying a laundry basket and grocery shopping). These relationships matured in my early adulthood stage, although relationships that began prior to that stopped maturing.

Parental Influence

Ironically, it is relationships with the people closest to me over the duration of my life — my mother and grandparents — that have had difficulty in maturing beyond a focus on physical characteristics. My mother and father challenged the small-town elementary school at which officials insisted I be placed in special education classes. Another student my age with CP also was entering the school. Her CP affected her cognitive abilities, and she was placed in the school’s special education class. It took a meeting between

my parents, me, and the school principal before convincing officials CP did not affect my learning capacity. I was allowed to enroll in the “regular” kindergarten class, if one could accurately define “regular.”

My father fought concern from local golf course professionals about how my golf spikes and crutches would tear up their greens and tee boxes due to my style of walking. The professionals were concerned that the way in which my feet moved when I walked could rip apart the manicured grass and the pressure I placed on my crutches would leave indentations in the greens. When I play, I place my weight on my right crutch and swing a club in my left hand. We were never a family that had full working knowledge of the laws of equality and the Americans with Disabilities Act of 1990. Yet my father was able to convince golf professionals at my hometown course that denying my right to play golf was not legally possible.

My parents never accepted the word “can’t” from me, so they were not apt to accept it from others. They encouraged me to attempt anything I desired. I was a member of a t-ball team, a youth baseball team, and two basketball teams albeit as manager and scorekeeper. My parents came to every game. My grandparents were equally supportive in my formative years. My maternal grandparents worked when I was an adolescent, but were never too exhausted for a game of baseball in the front lawn. We used a tennis ball so as not to destroy my aluminum crutch when contact was made. My grandfather was the pitcher and my grandmother the catcher as I swung with my left crutch as a pseudo bat.

I moved two hours away from home to attend college, and eventually moved five hours away to begin my professional career, during which the umbrella of protection from my family was removed. Yet traces of doubt from my family remain and sometimes appear to have increased since leaving home. When I return for family visits, I “can’t” wash my grandmother’s dishes because I will get too tired. I “can’t” clean the floor there because I am not able. I “can’t” wash my own vehicle when I go for a visit because I never did it myself when I was a youth, although I washed my car in college every week, alone, in the parking lot, sometimes on my knees scrubbing wheels. I “can’t” prepare my own dinner, my own plate, or my own drink when it is time for family meals, although I did as much throughout college and currently help my wife with meals in some capacity.

Reverting to a time when my family dictated what I could and could not do (e.g., external locus of control) may be their way of holding on to the past. However, since I moved out of my childhood home, my life has changed so dramatically that my mother and grandparents may not recognize it were it not for me sharing my stories. My college years were influential in formulating my identity because I was alone and without the cushion of immediate family support. More importantly, I was challenged. My professional years working in a large city in the Southeastern United States forced me to become more aggressive and direct, which is to be expected along any natural progression of a young

professional. However, I also began embracing my identity as a person with a disability.

Similar to relationships with my spouse, son, and college roommate, evolving relationships with my mother and grandparents relate to developmental psychology's stages of development. While I progressed professionally and socially into the early adulthood stage, my family continued to perceive me in the adolescence stage. The adolescence stage of development occurs between puberty and a full commitment to an adult social role in the working world (Rogoff, 2003). During this time, the individual begins to explore himself or herself by asking questions such as "Who am I?" and "Who do I want to be?" (Rogoff, 2003). Role confusion may prevent one from moving into the early adulthood stage, or in this case prevent my family's perception of my own movement out of the adolescence stage. When my mother prepares my plate of food for me at her home or my grandmother refuses to allow me to wash dishes because she perceives me to be unable, they are maintaining my place in the adolescence stage, a stage I was in the last time I lived under their supervision. I am firmly in early adulthood stage in my life, and have accepted commitment and social roles that identify with the stage.

Defining Self

I did not participate actively in accessible sports such as downhill snow skiing, water skiing, and handcycling until I was 30 years old. Within two years of being introduced to those three activities, I had snow skied twice in Aspen, Colo., water skied seven times, and purchased a racing handcycle to train with a U.S. national champion competitor. Participation in those activities and planning budgets and vacations around opportunities to participate became part of the fabric of my life. I am not at a competitive level in any of the activities, but I can claim to be recreationally fluent in all three.

Family support in this aspect has been critical. My mother and grandparents have babysat as we travel for recreational activities across the country and made extra time to spend at nearby lakes. They have listened to stories and stared at photographs as I try to relive my moments on the snow or in the water. However, they do not ask the question, "How do you do that?" which is the first reaction most have when I share my experiences. They also have not watched me participate in these activities. Having not experienced these activities with me or seen me participate may explain their difficulties in accepting me in the early adulthood stage. Yet it is these activities that now define much of my life.

I can explain the thrill of leaning forward off the ski lift, turning right, and then swishing down Big Burn at the top of Snowmass Mountain, the steepest blue trail I have encountered in my limited snow skiing experience. The adaptive snow ski is primitive, made of fiberglass that is painted and stamped with stickers. I am strapped in four times with Velcro belts. I use shortened crutches with tiny skis at the end, which transform them into outriggers. I can explain the difficulties of squeezing my body into the cage of an adaptive

water ski. It takes two people to help me push my backside into the seat of the ski, one to hold the equipment from the back and one to push me into the seat and then maneuver my bare feet into the tight, rubber foot harness. The cage is nothing more than padded bars molded into a strangely-shaped seat and bolted onto an extra-wide water ski. I use the water skiing version of outriggers, which are two skies on each side to provide balance. I know that I use a size 15 cage bolted three holes back on the board, and I use a rope with a ball so it remains hooked to the ski unless I can reach the rope and steer myself. Finally, I can explain why I spent more on the purchase of my handcycle than on my wife's engagement ring. It is a delicate piece of equipment, as I found out on my second ride when my turn radius was too wide, I hit a curb, popped my front tire, and destroyed my wheel. There are 27 gears on my bike, just like many other racing bicycles. There is an amazing amount of control when adjusting for camber, tire pressure, gearing, and other intricacies of which I am unfamiliar. My cycling mentor, from whom I purchased the bike, is a two-time national champion handcyclist who travels across the United States for competitions and has trained at the U.S. Paralympic facility in Colorado Springs, Colo. It is simple to get on the bike, but difficult to get off. I need help getting my feet from the foot harnesses, then slide off the side of the bike and onto the ground without the bike tipping over. I turn my body belly-down to move onto my knees and then maneuver myself into standing position.

The cultures of snow skiing, water skiing and handcycling have shaped my identity more in two years than anything I have ever done. They have shown me that I can participate in sport and physical activities that I once thought impossible. I can explain the effect each activity has had on my life, but it is nothing like the experience. When presented the opportunity to participate, the easy decision would have been to decline and keep my life safe and low-risk. I could have declined the opportunity to ski down a world famous mountain of snow or water ski on five different lakes or bike ride with a national champion. Had I defaulted to the "that's not possible" excuse, my disability would have defined me only because I would be allowing such. Instead, I chose to define my disability.

My personal challenge with internal locus of control with regard to my abilities relates to dialogical self theory (Hermans, 2010). The theory brings the notion of self by William James and George Herbert Mead together with the notion of dialogue by Mikhail Bakhtin (Hermans, 2010). By redefining self through participation in sport and physical activity, I took on the role of self-as-knower as described by Hermans (2001). My connections with the disability community were limited throughout my life, but my roles in adaptive sport better connected me with other individuals with physical impairments, many of whom had impairments that could be considered medically worse than mine. Therefore, I encountered individuality from within my own small disability communities because I was among the few ambulatory participants. I also encountered distinctness from others in my peer groups of able-bodied individuals as perhaps the only person with a disability and therefore the only participant in adaptive sport. Accepting the self-as-knower role,

I willingly made choices that dictated outcomes. I chose to participate in the adaptive sports for the internal gratification and for the external message it may reveal: people with disabilities can participate in extreme activities.

The Difficulty of Change

The purpose of this auto-ethnography was to reveal how instrumental life situations for a person with a physical disability present opportunities to define disability, rather than allowing disability to define the individual. I have identified instrumental life situations that capture how I have sought greater control of my life and how others appear to perceive me as a person with a physical impairment. I have attempted to use four theories that explain these instrumental life situations as they relate to seizing internal locus of control. These instrumental life situations and four theories can be categorized by (1) Building Relationships and Acceptance; (2) Evolving Relationships; and (3) Defining Self.

I will begin with Building Relationships and Acceptance. My working relationships remain professional due to colleagues and students whom I teach acting rational and considering implications before engaging in behavior such as questions about my physical impairment or making assumptions about my abilities, holding to the theory of reasoned action. Perhaps this is due to the educational setting and one that is diverse and welcoming to differences. College encourages challenging thoughts, but doing so on an academic level with positioned statements rather than blurting out the first thought or question that comes to mind. Conversely, my own perceptions of how I am accepted fit within self-categorization theory. My personal identity, as described in the theory, sets me apart from my peers professionally and socially as I am often the only person with a physical impairment within my social communities. My social identity, however, displays how I successfully portray characteristics aside from my physical impairment and am accepted into social categories such as the golf team, the group of college instructors, or a set of friends. With social identity, I am able to fit in without my physical impairment being the focus.

Next is the category of Evolving Relationships. From my current relationships, categorical walls may include disability but disability may not be the primary qualifier. I have attempted to define myself as a husband, father, student, instructor, researcher, group leader, writer, editor, and numerous other roles that I may not know. Participating in multiple communities reduces my outsider viewpoint and enhances my insider perspective, which can increase understanding of others (Rogoff, 2003). In those communities, physical impairment is not the primary quality I present for the group. To my wife, I am not the husband with a disability. To my son, I am not the disabled dad. To my colleagues, I am not the researcher or group leader with crutches. Quite simply, in the majority of those community roles, I am known for my abilities to love, decide, lead, find, distribute, and provide, none of which has to do with my physical impairment. These evolving relation-

ships set me in the early adulthood stage of developmental psychology, where intimate relationships are formed, therefore avoiding fear of commitment and isolation (Rogoff, 2003).

Conversely, those family relationships that have developed since birth appeared to pause when I moved out of my parents' home. My mother and grandparents rely on stories of my achievements. At the time of this writing, they had not seen me snow ski, water ski, or handcycle, therefore they had not transitioned their perceptions of me from the adolescent stage of development to early adulthood, relating back to developmental psychology. Many relationships in my life began in life stages during which I was operating as an independent adult; they were established when dependence upon someone or something for basic needs — food, shelter, social well-being — was nonexistent. I controlled my life when those relationships began (internal locus of control). For my parents and grandparents, they controlled my life when our relationship began (external locus of control). Therefore, the external locus of control kept me perceived to be in a role of adolescence on their eyes, and it has become an unrealistic expectation for them to shift perceptions of my abilities to early adulthood. This difficulty in shifting stages of development may hold true for several adults, no matter the level of ability, with regard to their family relationships. I argue that it is enhanced, however, for people with physical impairments due to the overprotective nature of a parent or grandparent who raised a child with a disability. Accepting that a dependent child has transformed into an independent adult has proved to be difficult and perhaps unattainable. I use my own family as an example not to chastise them for not conforming to my changing lifestyle, but to shed light on how difficult changing perceptions of disability over long periods of time can be even for the closest family members. Parents of children with disabilities should adhere to the changing expectations their child has of himself or herself. As the individual gains independency, parents should mirror that with encouragement or greater support rather than oppression.

Too many times adults with disabilities become complacent with their disability defining them and the roles they play throughout their lives. I use my own family as an example because it is often the family where this mind-set can harbor. Without the challenge or encouragement from my family at a young age, my experiences may have never been launched. Not transitioning their understanding of my ability has been exposed as my own definition of ability has advanced. Yet my own advancement would have never moved without roots of hope and possibility planted by my mother, my father who has since died, and three grandparents. Others may not be as fortunate. Still, a challenge lies in transforming established perceptions and beliefs. I chose to accept the self-as-knower role in dialogical self theory (Hermans, 2001, 2010). Embracing the opportunity for personal volition in participation is empowering and affects outlook in everyday life activities. Rather than depending upon others, choosing to take on personal challenges such as adaptive sport has allowed me to become more independent in my thinking and outlook in all aspects of life.

Discussion

As a person with a physical disability, perceptions are part of my life. Immediate perceptions must range the gamut when others first encounter me, and I am not naïve enough to believe I understand them nor am I in position to criticize them. It is natural for individuals to try to categorize and connect information to explain the unknown. We categorize people by gender, race, ethnicity, and ability, amongst other things, particularly in regard to minorities: the white basketball player, the black news anchor, the Mormon presidential candidate, the male hairdresser, or the disabled person. Why does the precursor (e.g., white, black, Mormon, male, disabled) have to be there? Does it add importance to the story? Should it be eliminated? These questions can only be addressed at a situational level, but should be at the very least considered by individuals in their discussions and activities. Once those categorical walls are constructed, they become difficult to shed. Eliminating descriptors may be the first step in eliminating damaging attitudes and actions toward minority populations (Patterson and Witten, 1987).

No matter the achievement, lifestyle change, or attitude adjustment by the individual with a disability, words are not enough to change others' perceptions. Actions alone are not enough, either. Consistent action of taking ownership in one's disability — or ability — may help shape internal and external perceptions. There have been and will continue to be countless times in my life when I could have opted for "I can't" and the opportunity would have passed by, but instead chose to redefine disability as it pertains to my life. Therefore, to challenge established perceptions, it is essential for the person with a physical impairment to seek control by defining disability before it defines them.

Auto-ethnographic Writing

The challenges in writing this auto-ethnography included the management of emotion and its relation to the research, maintaining a voice that may introduce a new view of the disability issue to others, and presenting a factual portrayal of my experiences. Ellis (1993) acknowledges similar challenges in her auto-ethnography of experiencing her brother's sudden death. Addressing such topics as family members' inability to change perceptions of my abilities were approached in the most objective manner I could offer to prevent unsuspecting emotion from weaving its way into this writing. While emotion is an important quality of auto-ethnography (Creswell, 2007; Ellis, 1993), I attempted to prevent feelings from clouding my judgment as a researcher in analyzing the "why" behind actions and perceptions. Similarly, I attempted to recount my experiences from a factual recall. For each vignette provided, I asked myself if a third party could discover much of this same information through conversations with others or in-depth investigation. However valid it may be, this attempt at providing factual information kept me grounded in representation,

objectivity, data quality, legitimacy, and ethics, all areas of concern for auto-ethnography as described by Wall (2008).

Like Ellis, my goal was to expose a topic to stimulate discussion from a fresh perspective. Disability is not a new topic of study, but first-person accounts of how disability affects one's own experiences presents a unique opportunity to compare and contrast the experiences of others. As Ellis (1993) explains, "the 'truth' of this story then lies in the way it is told and the possibility that there are others in the world who resonate with this experience" (p. 725). I am not naïve to believe someone else's experiences are the same as mine, as generalizing these experiences is a limitation of auto-ethnography (McIlveen, 2008). However, sharing my experiences may create a position to which others may relate with regard to perception and disability.

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