

**Review of Disability Studies: An International Journal**  
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## Introduction

### *Review of Disability Studies (RDS)* **Deep Impact: Pacific Rim Forum**

Katie Aubrecht, PhD  
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The International Pacific Rim Conference (Pac Rim) on Disability & Diversity, held annually in Honolulu, Hawaii, has been widely recognized over the past 30 years as one of the most diverse gatherings in the world. The event encourages and respects voices from diverse perspective across numerous areas, including: voices from persons representing various disability areas; experiences of family members and supporters across various disability areas; responsiveness to diverse cultural and language differences; evidence of researchers and academics studying disability; stories of persons providing powerful lessons; examples of program providers, natural supports and allies of persons with disabilities; and, action plans to meet human and social needs in a globalized world.

This RDS Forum represents a sampling of outstanding disability studies presentations from the 2015 Pac Rim Conference, themed "Deep Impact." The 2016 conference, "From the Margins to the Center", will be held at the Hawaii Convention Center on April 25th and 26th (additional information on the conference can be found using the following web link: [www.pacrim.hawaii.edu](http://www.pacrim.hawaii.edu)). Across the four research articles, the multimedia piece, and the poem selected for inclusion in the Forum, a conception of disability as an *identity juncture* emerged as a common theme. Disability is imagined as a critical and decisive turning point that disrupts unexamined relations to self, other and society, and conditions the possibility of new ways of relating. Each of the works takes up the 'deep impact', the social and symbolic significance of this juncture in different ways.

In "Using the International Classification of Functioning, Disability and Health (ICF) to Improve Understanding of Disability and Functioning," Patricia Welch Saleeby describes the global impact of a powerful way of identifying and responding to disability and disabled people. The ICF is a framework developed by the World Health Organization (WHO) to measure health and disability of individuals and populations that includes health domains and environmental factors (WHO, 2015). As Saleeby notes, problematic aspects of the ICF have been raised in disability studies. For example, Rob Imrie (2004) suggests that one of the limitations of the ICF is that it has been undertheorized, and that there are components of the ICF that require further conceptualization and clarification. In her descriptive analysis of the ICF, Saleeby suggests that components of the ICF align with a social model of disability and shows how the ICF can be used as a tool to understand the relational and contextual dimensions of disablement. Her reframing the ICF as a tool that directs attention to the social and environmental dimensions of health and disability has implications for how disability is identified within public health and social service perspectives. It also has the potential to 'impact' how the WHO is identified and understood within the field of disability studies – as a body that is both medical and oriented by a social model of disability.

Keisha Rogers, Rahim Skinner and Brenda Cartwright engage the identity juncture via a critical examination of the systematic oppression of culturally diverse students and faculty within university environments in their paper, “Strategies to Create a Culturally Responsive Learning Environment.” The figure of disability as the product of a failure to recognize and respond to cultural difference animates in their analysis of a workshop titled, *Keeping it Real: Illusions of Equality and Injustice on College Campuses*. Their interest is in the impact that personal accounts of discrimination and exclusion that are shared within the context of culturally responsive education and training programs and practices can have on the treatment of culturally diverse and disabled students and faculty. They conclude their paper with a list of strategies for environmental and cultural change within universities that promote self-reflection and transformational learning in the interest of supporting equity and reciprocity of relationships.

In “The Spoken Word and Emotion in Communication,” Karen Roberts shares her understandings and experiences of the transformative, creative and generative potential of what she describes as *spoken word*, and which she defines broadly as a performative art form that includes storytelling, music, cabaret, and theatre. Roberts describes how she has used her art as a means of crossing boundaries between self and other. In doing so, she identifies spoken word as an art form that offers an outlet for emotion and self-expression, while at the same time evoking emotion and shared understanding in her audiences.

Douglas Kidd recollects and reflects on the significance of trauma as he experienced it in the form of a traumatic brain injury that resulted from a car accident in, “Disability Studies Influence on a Profoundly Altered Identity.” Through his moving narrative, Kidd recounts his experiences of survival and living with traumatic brain injury, and how they were shaped not simply by changes in functioning, but also by alterations in his awareness of his surroundings, his sense of self, and of time itself. Drawing on Alison Kafer’s (2013) understanding of how disability renders time queer, Kidd details the emotional affects of temporal dissonance as he experienced them within the context of sudden onset of impairment, and how at times this dissonance took the form of perceived disembodiment. He concludes with his understanding of having experienced a destabilization of identity and emotions as foundational to a transformation in his relations with others and his world, and the field of disability studies as a critical support that he used to negotiate this process.

Steven Brown’s poem “Devastate/Celebrate” depicts the violence and disenfranchisement, systematic exclusion and denigration of disabled persons in an ableist society. However, Brown also notes that even as oppressive social structures and environments shape how disability is experienced, they do not determine it. Through collective struggles for rights and recognition, disability communities have redefined disability and reclaimed disability history, creating space to live, to thrive and to dance. This is cause for celebration.

In “Towards Cultural Inclusion: Using Mobile Technology to Increase Access to Audio Description,” Thomas Conway, Brett Oppegaard, and Megan Conway discuss a mobile application for audio describing National Park Service print brochures in Hawaii. They suggest that this application provides a means of enhancing the experiences of visually impaired park visitors addressing the failure of normative approaches to accessibility that treat access to

cultural and aesthetic experiences as a luxury, rather than a right.

One of the definitive characteristics of understanding disability as an identity juncture concerns the way it can turn us towards greater recognition of the power and possibility in turning, re-turning, and of having been turned towards how. The works in this Forum engage the profound impact that environment, culture, communication, contingency, technology and the law can have on social understandings of disability, and the experiences and self-perceptions of disabled people. They also suggest that what disability and disablement mean are routinely negotiated, challenged and redefined in varied and discontinuous ways, from multiple and even contradictory perspectives. The collective impact of these works is perhaps best understood in terms of their exemplification of Tanya Titchkosky's notion of disability as an "activity of perception" that can provoke a sense of wonder about how disability is imagined in the ways that it is (2011, p. 59):

"Disability is the activity of perceiving and thus representing how we orient to, for example, certainty and ambiguity. As we perceive through disability, then, all of us are intimately a part of what disability becomes in our perception. Disability exists in the midst of this perception, in the midst of people, and in the perception that flows between them. To understand disability as created in the liminal space between self and other allows us to address the confines of contemporary representations of disability, including the oppressive ones."

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## Research Articles

### **Towards Cultural Inclusion: Using Mobile Technologies to Increase Access to Audio Description**

Thomas Conway, PhD, Brett Oppegaard, PhD, & Megan Conway, PhD  
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**Abstract:** This paper describes a National Park Service (NPS) and University of Hawaii research project that is developing a mobile application for audio describing NPS print brochures for blind and visually impaired park users. The project has the potential to expand access to cultural and aesthetic material for blind and visually impaired people.

**Key words:** accessibility, assistive technology, blind and visually impaired

#### Introduction

Creating access for people with disabilities by public and private entities in the United States is most often driven by the compulsion to meet the minimum requirements of the Americans with Disabilities Act (Jones, et al., 2012) and other Federal and State civil rights laws. Often the focus of accessibility efforts is on the obvious and the essential. Can someone in a wheelchair get into a building to conduct business? Can someone who is blind or visually impaired independently ride the bus or read a government webpage? Access to cultural and aesthetic content is usually seen as a luxury rather than a right. This oversight deprives many people with disabilities from social inclusion, recreation, and the benefits that cultural and aesthetic pleasures bring to an individual's quality of life.

Audio description is a means of providing people who are blind and visually impaired with a verbal synopsis of visual content. Audio description has been most widely utilized as a narrative technique for providing visual access to live cultural events such as movies and theatrical performances. However, audio description is largely underutilized for more static visual material such as museum displays, outdoor attractions, and image-dependent brochures. The lack of audio-described material is due in part to the time-consuming and specialized process of describing visual content using human actors.

The National Park Service (NPS) is funding a research team from the University of Hawaii at Manoa to use mobile technology as a platform to offer audio described park service brochures for people who are blind or visually impaired. Mobile technologies make it possible to more efficiently and affordably create audio description content that is uniform, portable, and easily adjustable to meet the needs of individual users. Challenges include developing a best practices protocol on audio description for NPS personnel, applying accessibility guidelines, and developing a user-friendly application for both the content providers and blind and visually impaired audiences.

### Need for Alternate Format Brochures

The NPS has 342 brochures that are designed and produced in collaboration with their publication house in Harper's Ferry, West Virginia. The NPS uses brochures not only to convey basic information about the park, such as park hours, hazards, and the location of campsites and visitor centers, but also to give the visitor a sense of the historical, natural, and cultural significance of the park. Increasingly, this is done through the use of highly visual media such as photographs, maps and drawings. NPS brochures are seen not only as a tool for use by visitors while they are in the park, but as an aesthetically pleasing souvenir for park users to take away with them when they leave (Hartley et al, 2015).

Currently the NPS offers large print, some Braille, and a few audio described brochures for blind and visually impaired people. The Americans with Disabilities Act (ADA) and Section 508 of the Rehabilitation Act require federal agencies to make alternative and accessible formats of information offered in print and on the web (Schuur, 2001). There are no specific mandates about best practices for achieving high quality print access (Lazar, Goldstein, & Taylor, 2015). According to the American Foundation for the Blind (AFB, n.d.), in 2012 there were over 20.3 million adult Americans with a visual impairment. In keeping with the NPS effort to offer broad access to the park system to a wide range of people, the NPS is actively developing alternative formats for their Park site visitor displays, videos, and printed materials.

### Project Goals and Description

With the increasing popularity of mobile devices in the United States, using software programs via mobile technologies, such as smartphones and mobile apps, offers the opportunity to engage with alternate, and potentially accessible, applications for personal and on-demand use. Bouyed by the growing use of mobile technologies, this NPS project will develop an application for delivering audio-described Park Service brochures in an economical and efficient mode for blind and visually impaired park users.

There is limited research and real-world guidelines for creating audio described print materials (Braun, 2011; Morales, 2011). One of the NPS project's goals is to develop a best practices protocol for creating usable and current output in a repeatable and consistent manner. Existing research and documentation falls into three categories (Szarkowska, 2011): 1. soundtrack audio description options for film and television production; 2. live theater performance audio described recordings, and 3. museum tour guided programs directed toward blind and visually impaired visitors. There are currently no national or international standards for providing consistent and high quality audio description (Orero & Vilaró Soler, 2012; Morales, 2011).

The backend software program for creating content for audio output to a mobile device application will require NPS personnel to input data into an online tool, created during this process, providing an opportunity for step-by-step instructions based on a set of best practices. This NPS project will implement recognized international accessibility guidelines from the World Wide Web Consortium (W3C) Web Accessibility Initiative (WAI) ([www.w3c.org/WAI](http://www.w3c.org/WAI)) to bring the software applications in compliance with the ADA and Section 508 regulations and

will be used to contextualize the final best practices documentation. However, the project also will go a step further by collecting, analyzing and integrating the existing ad hoc best practices in audio description with project research on best practices so that blind and visually impaired end-users will have a high-quality audio-described brochure that provides them with the same informational, aesthetic and cultural experience intended for sighted users.

Finally, the NPS project's software prototypes will be tested by NPS personnel and blind and visually impaired users at three NPS sites for evaluation and feedback. Using real NPS sites for testing will bring together best practices protocols for creating content with blind user preferences for access and engagement. Our hope is that such research and testing in practical situations will provide an opportunity for rich dialog on improving audio description and mobile technology and thus contribute to the knowledge base on audio description.

### Implications

Providing an audio-described brochure for blind and visually impaired visitors will expand NPS reach to people with disabilities wishing to experience and enjoy the parks as other visitors currently do. The National Parks offer a social context that is supposed to be educational, historical, and entertaining for all people. This project has the potential to significantly enhance the park experience for blind and visually impaired visitors by enabling them to explore and engage in the social and cultural opportunities that the parks provide. This project also will put the NPS at the forefront of the accessibility field, as media becomes increasingly visual and less dependent on the written word for communicating to the general public.

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## Disability Studies Influence on a Profoundly Altered Identity

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**Abstract:** This article describes circumstances of my traumatic brain injury, the aftermath, expressions of the brain damage acquired, and current functioning. The article examines the influence exposure to Disability Studies scholarship made to precipitate development of a disabled identity. The article explores advocacy efforts that are my direct response to society.

**Keywords:** Traumatic Brain Injury, Acquired Disability, Identity

### Introduction

On Sunday, May 17, 2015, while in Kailua, Hawai'i preparing to present to the Pacific Rim conference, I celebrated the tenth anniversary of the catastrophic car accident that irrevocably and profoundly altered me and the course of my life. It is difficult to imagine how one could possibly celebrate a catastrophe, because for two and a half months, I experienced states of either coma or amnesia. As I slowly emerged, I regained the ability to process the world around me and expressed joy in reunion with family and friends as I recognized the extraordinary opportunity I had to live. The tremendous upheaval accompanying survival and living in the aftermath of a severe traumatic brain injury (TBI) provides stark contrasts between loss and gain, despair and hope, grief and joy, death and re-birth. Because of the contrasting extremes the accident heightened, I am grateful for the depth of understanding I have regarding the rich experience of simply being alive.

In order to provide context for describing experiences of survival and living with traumatic brain injury in this essay, I provide the following brief description the circumstances of the accident and the injuries I acquired. At 4:34 PM, Tuesday, May 17, 2005, I initiated a cellphone conversation to my brother as we made our separate ways to a golf course. I planned to arrive at the course first, so I am sure the conversation discussed some last minute and trivial details about the outing. I do not recall the accident because a massive SUV (figure 1) travelling about 50 miles per hour slammed into the left side of my small car (figure 2) after I paused briefly at the stop sign before proceeding into the intersection. Everything happened in a blur, leaving me no opportunity to process the event. The driver and sole occupant of the SUV was uninjured. She bore witness to the horrific scene and reported it to rescue personnel. I have been informed that the energies of collision were so terrific my car eventually came to rest in a field dozens of feet from the point of impact.



*Figure 1 Photograph of the minor damage to the SUV after the accident*



*Figure 2 Photograph of Douglas Kidd's car after the accident. One can see the massive damage that was caused by the collision*

The consequences of the accident were devastating. Major injuries I sustained included: multiple hip fractures, a crush injury with compartment syndrome (increased pressure in a muscle compartment that can lead to muscle and nerve damage as well as blood flow problems) to my lower right leg, ruptured spleen, bleeding behind my abdomen, lacerations to my liver and rectum, and two cardiac arrests (one at the scene, the other soon after arrival in ER). The most significant injury occurred as my head absorbed enormous energies from the SUV and my brain hemorrhaged severely. Days later while in ICU, a deadly methicillin-resistant staphylococcus aureus (MRSA) infection took hold. I came so close to death from MRSA, and survived, staff at the rehabilitation hospital referred to me as the “miracle man.”

I now turn to descriptions of life following my accident. For many days, a tube extended through my mouth and into my lungs, as a machine breathed for me. Weeks passed, turning into a second month, and while far from conscious, I steadily gained a sense of the world around me. As I became more active, a tracheotomy tube was inserted in my throat that breathed for me. In addition, a g-tube became a pathway to deliver food and medicines directly to my stomach. After stabilizing from the initial trauma, I experienced coma for 24 days, followed by amnesia for 45 days. As comas lasting longer than three weeks are rare, I am extremely fortunate to have survived.

A significant injury developed when my lower right leg became crushed against a car panel and burst open. I cannot place a specific memory associated with therapy to treat the wound, but at the edge of awareness, was the incessant sound and unpleasant smell emanating from the device surrounding my right leg. I've no doubt the machine saved my leg, but it forms a

hazy memory of the time when I began to surface. It is curious to note, a strong smell like rotting garbage, and an incessant humming noise, stimulated my initial reconnection to the world and welcomed me back to life.

What I am sure was a gradual accumulation of days where I increasingly became more aware of my surroundings, looking back seems like a switch turned and I surfaced fully one day in late July, 2005. About three months after the accident, I initiated conversation with a nursing facility aide. For reasons I could not explain, I had the vague impression I did not like him much. He suggested my dislike for him likely occurred as I steadily regained consciousness, frequently fighting against him. He explained, with no awareness of what had happened to me, or my current circumstances, that I became disoriented, agitated, and actively began to resist treatment. One day, I managed to rip the trach tube from my throat and tumbled out of bed. Following this incident, for my own protection, restraints limiting my mobility were used. As my discharge from hospital approached, I arranged to meet the man. I wanted to thank him for helping me when I needed it and apologize for my behavior. He welcomed my appreciation of his efforts, assured me there was no need to apologize to him, and we parted as friends.

I have no distinct memories of the states of coma and amnesia I experienced for two and a half months. Occasionally, images form of lying in a hospital bed, tubes keeping me alive, restraints in place, with me fighting desperately against them. These imaginings often produce a flood of raw emotion. I am truly okay with the crying episodes that frequently occur; because I recognize tears as the natural expression of the brain damage I acquired. At times, I do not have to recall the past to break into tears. A beautiful melody, or a touching scene from entertainment or a book, or expressions of love and regard exchanged between people, overwhelm the logical and rational parts of my mind and I dissolve in tears. Often, sharing among friends becomes too much to process without my mind blanking and a flood of raw emotion ensuing. When I reflect, strong emotional responses occur when I witness or contemplate expressions of human warmth and kindness, along with prospects and efforts made in support a hopeful future. I have come to treasure tears for their ability to place the experience of being alive into stark relief. My emotional delicateness is an outcome of the brain damage I acquired, defines my reality, and forms a significant aspect of my new identity.

Before providing examples of my emotional delicateness, I turn to Disability Studies scholarship to describe my experience of acquiring multiple disabilities. Disability Studies has helped me make sense of how this event drastically altered my identity, my sense of self, and largely describes my life. Alison Kafer (2013) provides a theoretical framework to understand aspects of my experience. In her book *Feminist, Crip, Queer*, Kafer suggests disability renders time queer (p. 34). Applying this notion to my circumstances, the magnitude of brain damage caused me to experience extended time dilation while in states of either coma or amnesia. As my brain absorbed enormous energies from the SUV, weighing more than six thousand pounds and travelling 50 miles per hour when it slammed into me, the delicate electro-chemical structures of the neurons of my brain experienced massive damage, disorientation, and I existed for months without a sense of passage of time (Chevrolet, n.d.). As the trauma, coma, and amnesia subsided, my new identity became profoundly altered. Somehow, as I “filtered” back through the damaged brain tissues, enough neurons realigned, and finally I surfaced. While my new identity’s awareness of time has largely returned to pre-accident levels of acuity; the glaring exceptions

noted below, provide examples of the disorientation my brain at times experiences. In addition, my experience confirms and offers as example Kafer's suggestion (2013, p. 34):

“Not only might they cause time to slow, or to be experienced in quick bursts, they can lead to feelings of asynchrony or temporal dissonance; depression, and mania are often experienced through time shifts, and people with various impairments move or think at a slower (or faster) pace than culturally expected.”

As confirmation of Kafer's suggestion, at times I experience symptoms of Major Depression and mania, because as I attempt to process my surroundings with drastically altered cognitive, emotional/psychological abilities, my brain moves at a slower speed, out of step with other people.

An example of my previously referenced emotional fragility, which reflects Kafer's discussion of asynchrony or temporal dissonance impaired individuals experience, occurred shortly after I returned home from the hospital. It was at the end of a long day in late-January 2006. As I lay in bed, my mind raced and I caught my reflection in a mirror. Suddenly, it felt as if the bottom dropped out of my life and I hovered above the yawning abyss of my unknown future. This experience terrified me greatly. My only response was to burst into tears, and my entire body shook for 15 minutes. As I reflect, this was an example of my brain attempting to process the multiple aspects of my newly recovered life, emerging identity, and my mind simply quailed. Clearly, I had difficulty processing the pace of my new life. This is hardly surprising considering the severity of my injuries. It had been only four months since I left the hospital, eight months since the accident, and I returned to work fulltime while attending college part time.

Illustrating Kafer's idea that impaired individuals experience asynchrony or temporal dissonance, another example of my emotional instability occurred when I attended a concert at Millennium Park in Chicago in late-August 2008. It was a perfect summer night and I lay on the ground looking up at the stunning skyline of Chicago. As I marveled at the beautiful sky, and amazing latticework structure that seems to float in air above the pavilion lawn, I found myself thinking about all that I experienced since the accident and became unable to contain the flood of emotion these thoughts produced. I felt I was somehow disconnected from my body, helpless to control my tears for about fifteen minutes. I do not accept “out of body” experiences; but I distinctly recall thinking while in that emotional state that it was someone else who cried uncontrollably, and as much as my heart ached for him, I could do nothing to stop his tears. It occurs to me, the emotional breakdown I experienced that night was in part due to a sudden remembrance of all the pain I experienced during and following the accident, and yet, at the same time, I was overwhelmed with joy because, against tremendous odds, I had the opportunity to live my life again. I made it through an incredible ordeal with a chance to share in all the joys and sorrows life can bring.

This happened the Saturday before I would begin working as a graduate assistant for the Disability Studies program at the University of Toledo, and so it was hardly surprising that I experienced such an emotional outburst. Prior to Chicago, given the severity of my brain injury, I felt insecure about my ability to perform graduate level work. As I reflect, a significant feature of

my traumatic brain injury is uncertainty over my ability to cope with life's pressures. That night foreshadowed later difficulties I would experience as a graduate student.

While I am largely content and happy with my life, it is impossible for me to ignore how the accident completely disrupted the course of my successive development, where first days of life became years, decades passed, and I grew older with continual awareness of my past, present, and I developed a plan for my future. Kafer suggests impaired individuals encounter disconnects in the timings of their lives when she writes, "These shifts in timing and pacing can of necessity and by design lead to departures from "straight" time, whether straight time means a firm delineation between past/present/future, or an expectation of a linear development from dependent childhood to independent reproductive adulthood (p. 34). As mentioned the course of my life since the accident largely follows the straight time path Kafer suggests. However, the two major episodes referenced above - at home shortly after hospital discharge and Millennium Park in Chicago - as well as other minor episodes not described here, clearly indicate instances where the brain damage I live with compels drastically altered experiences of reality which had never occurred before the accident.

An incident that occurred about two and a half years after my accident provides a window into my cognitive functioning, emotional sensitivity, and provides an example of Kafer's discussion of impaired individuals' thinking as slower than culturally expected. I mention this as an example of formerly impaired cognitive ability because now that I have recovered enough, this would not likely occur. At the time, I believed everyone, even strangers, conducted their affairs honestly and never did anything to threaten or harm others. General belief in the goodness of people remains problematic for me; but as I returned home, a stranger caught my attention and requested assistance. The man said his car had run out of gas some distance away leaving his wife and two children stranded in a city they did not know. He asked me if I had money for gas. Truly, I did not have enough money on me to give him, but volunteered to take him to an ATM. Fortunately, the ATM was some distance away. This gave me time to examine the man closely where I read his nonverbal cues: he seemed nervous, detected poor hygiene, saw his tattered clothing, and through conversation observed, he made several contradictory statements. Soon, I became alarmed as I realized I planned to take the man to an ATM where he might subsequently rob me. A few weeks prior, I learned in terms of per capita income, the area where I live is statistically among the poorest in the United States. Weighing all these factors, as soon as I could, I found a shopping center crowded with people, stopped the car, opened the door, and exited. I now felt comfortable he would not attack with others there to potentially intervene, so I instructed him to get out of my car. After arriving home, I shuddered, thought what might have occurred, then collapsed in tears.

In addition to the issues of emotional instability and cognitive impairment described above, the traumatic brain injury I experienced completely shattered my identity, or sense of who I am. This may seem an unlikely statement, and possibly difficult to accept because my long-term memories are largely intact. To all appearances, I recovered my life and I seem "normal." Nevertheless, the brain damage I experience greatly affects my ability to make physical, cognitive, and emotional adjustments to society. Especially during early days of recovery, I had tremendous difficulty with brain processing speed, concentration, speech aphasia, emotional stability, and an experience common for many traumatic brain injury survivors - grief over the

loss of my former self. Rudi Coetzer suggests traumatic brain injury survivors have trouble with emotional adjustments as they attempt to reintegrate back into society. Coetzewr explains survivors experience dislocation from society by having impaired self-awareness, loss, grief, and finding meaning in their lives (ix, x, 12). Living with limited self-awareness, loss, grief, and finding meaning in my life are the principal dislocations to my identity that I experience. The quality of grief accompanying a severe traumatic brain injury is the salient issue I've encountered in my recovery and is difficult to describe. In my case, use of the word "grief" is apt because a central part of my identity greatly desires to function as I once did, but in reality, I never will. This is difficult to accept. Accordingly, often I experience great sadness and mourn for the person I used to be. This seemingly contradicts statements made about accepting impairment, and approaching life with a positive outlook, and I am grateful for the tension grief adds to my life; but I am largely able to disconnect from mourning, and the dominant part of me strongly insists on survival.

As mentioned previously, the traumatic brain injury I experienced completely shattered my identity. I reference Dominick LaCapra's (2006) scholarship to expand on this idea. LaCapra says (p. 236):

"With respect to identity-formation, one should make special mention of the founding trauma in the life of individuals and groups. The founding trauma is the actual or imagined event (or series of extreme or limit events) that poses in accentuated fashion the very question of identity yet may paradoxically become the very basis of an individual or collective identity. ...it (founding trauma) may also become the basis of a new identity."

As I reflect on these words, while my new identity is largely established, the brain damage forced me to lose the sense of who I was and more importantly, who I am. I lost the common filters and/or safeguards developed to navigate relationships, which I learned as I grew older. This causes me to experience significant social disconnections and difficulties. However, I successfully maneuvered around the damaged brain tissues, or rather created new pathways through to compensate. It is an everyday and ongoing process of recovery to claim my new identity.

Before examining my decision to pursue a graduate degree in Disability Studies while living with severe traumatic brain injury, I need to describe a relationship critical to my acceptance of disabled people. On December 31, 1987, my brother Richard as a pedestrian attempted to cross a street in Indianapolis when a hit and run driver without headlights collided with him. Richard experienced multiple compound fractures to both legs and a severe closed-head traumatic brain injury. Additional complications occurred as Richard stopped breathing for an unknown period before rescue personnel arrived. As a result of the collision, Richard acquired massive brain damage, resulting in a coma lasting approximately eleven months. Due to the extent of brain damage, Richard cannot process the passing days, is hemiplegic, and is only able to control the right side of his body. Richard does speak and possesses many long-term memories, but requires prompting.

I need to reference Richard's experience here because before my accident I was nondisabled, regarded him as other, distanced myself from his needs, and excluded him from my life. Richard became a doorway to loss and pain. In spite of the fact he used to live within ten miles, I would go months, sometimes years without seeing Richard. Now, rarely a week passes, but that I don't see Richard, and I continually look to his care. Where I largely encounter impairment, society disables Richard. However, as my recovery progressed, and I gained independence and mobility, I often visited Richard. Richard became the touchstone of my identity as a disabled person, his life anchors mine, as someone I love dearly, and as a fellow traumatic brain injury survivor his experience resonates deeply. I did not realize this at the time, but unconditional acceptance of Richard signaled the foundation of my new identity as a disabled person.

Since emerging from the coma and amnesia at the rehabilitation hospital, I've been driven to recover as much of my life as quickly as possible. I returned to work fulltime, as an aluminum die cast designer and part time student, within eight months of my accident. Then, in favor of completing my degree, I abandoned a decades-long career I'd worked in or towards since aged fourteen. As I actively sought employment for more than a year following graduation from college I came up against a startling statistic: unemployment levels for disabled people are more than 60%. However, employment opportunities improve for those who are able to achieve a Master's degree. In order to increase my opportunities for employment, as well as promote recovery of my brain, in early 2008 I applied for the Master of Liberal Studies with a concentration in Disability Studies degree program at the University of Toledo. Additionally, I applied for the program's Graduate Assistant position. Later that summer, I learned not only had I been accepted to graduate school, but would begin fall 2008 semester as a Graduate Assistant. These two events became pivotal to my continued recovery from severe traumatic brain injury and precipitated development of my disabled identity.

Prior to graduate school, I could not anticipate how the experience would profoundly alter my consciousness. Exposure to Disability Studies scholarship as I understood it through the works of Erving Goffman, Paul Longmore, Ed Roberts, Simi Linton, Mike Oliver, Lennard Davis, Rosemarie Garland Thomson, Jim Ferris, Thomas Couser, Susan Burch, Kim Nielsen, Ron Amundson, Rachel Adams, James Wilson and Cynthia Lewiecki-Wilson, Sharon Snyder and David Mitchell, provided me with a depth of understanding of the lives of disabled people and their treatment/mistreatment by society through history. As my new identity became exposed to ideas presented by the scholars above, I internalized Disability Studies paradigms and concepts much like an organic process. In keeping with the idea of a natural progression for my brain's recovery, if graduate school served as the trellis I desperately clawed my way up, clung to, and spread outward upon as my brain recovered cognitive, psychological, and emotional abilities; then Disability Studies became the sun, air, minerals, and water that nurtured, suffused within me, and served as catalyst to construct my new disabled identity.

One illustration of this idea is that my understanding, sensitivity, and response to stigma occurred gradually as I re-engaged with society. For example, during the first few months after the accident, I did not try to hide the physical disfigurements I possess. However, as time passed, I developed a very different response to the feedback my scars provoked. On the one hand, there is a dramatic scar on my lower right leg more than a foot long, which tapers to an inch wide and

nearly a half inch deep. Yet, I am not sensitive to displaying the scar; in fact, I often wear shorts and choose to show this scar. I do this because the scar signals to myself, and others that I have come through extraordinary circumstances, which in turn feeds my positive self-image. Alternatively, there is the scar on my neck made to accommodate the tracheostomy tube. In the first months after I surfaced, I did not care how others perceived this scar and did not bother to conceal it. However, one day at a physical therapy session, a man stared at the scar continually for more than thirty minutes. My fragile identity did not permit me to disregard or challenge him, but I became extremely uncomfortable because he stared for a prolonged time at the scar on my neck. I concealed the scar as soon as I could, and unless it's a rare day spent at a beach or pool, the scar remains hidden. I offer this explanation for my very different response to these scars. The scar on my leg is about one hundred times larger than the scar in my throat, so clearly, size is not the stigmatizing issue; but the scar left by the trach tube is a near-facial disfigurement, and I am overly sensitive to the stares this scar evokes.

Feelings of inferiority surface and I desire to hide from the gaze of others when I reflect on negative feedback from others regarding some of my physical disfigurements. This is an example of how my fragile self-image and uncertain identity attempts to manage my surroundings. Stigma permeates our culture, and prior to graduate school I possessed only a general understanding of the term; but knowledge gained as I absorbed Disability Studies scholarship, especially Erving Goffman's seminal work, provided me with the theoretical framework to fully understand the concept I internalized when my physical disfigurements produced the social response (Goffman, 3).

Further illustrating my emerging disabled identities' development as a natural reaction to Disability Studies scholarship are evidenced by sensitivities I developed towards limiting environmental structures and the advocacy efforts I have made in response. For example, on my way into work as a graduate assistant one day, I observed a new construction site at the university. The most striking aspect of the site was placement of large waste containers squarely on the few accessible parking spaces in the area. As the containers stood there for weeks, evidently without report from others, I documented their placement one weekend, then sent the images to the appropriate university office. As soon as the facilities manager received the photos, the waste containers were removed.

Another advocacy outcome developed in response to sensitivities I developed as a disabled person. As I used public transit to travel to the university one day, I observed several deficiencies at the suburban bus stop platform located adjacent to the area's major shopping center. As member of a city/county disability commission, I initiated efforts that led the mall to improve its accessibility. My awareness of advocacy efforts learned in Disability Studies courses, combined with personal experiences of impairment, led me to seek improved access to the mall for the community. It is not necessary to be a traumatic brain injury survivor, and serve disability-related organizations seeking to improve structures that limit individuals; but it took me eighteen months to regain the ability walk again. My new identity as a disabled person finds me acutely aware of structural barriers, and I do not hesitate to seek improvement of restrictive environments and facilities.



In my former work as a Peer Support Specialist, and current employment as a Qualified Health Home Specialist for a large healthcare provider committed to supporting and empowering individuals, I daily affirm my disabled identity as a traumatic brain injury survivor, and validate knowledge I gained as I pursued a graduate degree in Disability Studies. While the job description to work as a peer supporter with individuals living with symptoms of Severe Persistent Mental Issues (SPMI) does not require a master's degree, it does demand lived experience of significant emotional, cognitive, or psychological impairment. In addition, the work I performed as a graduate student in Disability Studies provided a good conceptual framework for my complete acceptance of the individuals I assist. These factors support me well as I provide a crucial point of connection for individuals seeking treatment and directly support their ability to live and thrive in the community. A significant example of the strength of peer relationships is evidenced by the fact an individual withdrew from psychiatric treatment. Several months passed and the individual reached out specifically for my help as they looked to resume treatment. My former work as a peer supporter is the culmination of many years of effort of recovery and would not be possible without complete acceptance of my new disabled identity.

Looking back, my newly formed and fragile identity came under tremendous stress as I attempted to meet the demands of being a graduate assistant and a student with slowed processing speed issues caused by the traumatic brain injury. Preparing for class, completing assignments, and my obligations as a GA compelled me to work seven days a week and fourteen-hour days were routine. I soon exhibited several symptoms of major depression, i.e. loss of appetite, sleep difficulties, continual sadness and crying, as well as diminished self-worth. However, given my ability and desire to survive, I never considered self-harm. The main reason for this is that even while experiencing despair; I said to myself, "Douglas, while the severe traumatic brain injury you acquired is an enormous challenge, you have requisite skills, you innately know how to survive, so take heart, be patient, you will succeed." In addition to these daily positive self-affirmations, shortly after graduate school began in September 2008, I attended weekly meetings with a counselor. These therapy sessions helped me immensely learn how to focus on the work, believe in myself, and take time to relax and enjoy the college experience. While continually reminding myself of these ideas, the first year of graduate school was extremely difficult. I informed instructors about my injury, registered with the university's Office of Accessibility and received accommodations. With these supports in place I survived my first two semesters. However, given my limitations, the graduate assistantship ended with the school year. Nevertheless, with great effort over the course of the next semesters, I developed a reading strategy that assisted me with course requirements; and by working with a psychological counselor every week to maintain emotional stability, I knew I would eventually succeed. It took me four years to complete my graduate degree; but in the end, the experience shaped my new identity by providing avenues for me to reconnect with society as a disabled person.

From some of the negative aspects of surviving and living with a severe traumatic brain injury described above, it is difficult to imagine how I could possibly regard my experiences as a net positive. However, as I experienced great emotional turmoil and upset while I pursued the graduate degree; it was difficult for me to recognize how my daily efforts greatly enhanced the recovery of brain tissues and restructured damaged neural pathways that hemorrhaged in the accident. It is impossible for me to ignore the tremendous cognitive growth and emotional stability I experienced and now enjoy because of my efforts in graduate school. The brain

damage caused my identity to experience such tremendous and dramatic change that the effect of accident continues to the present day. So much so that I never intentionally refer or conceive of the injury to my brain in the past tense. Principally because the daily complexity required to process, and then interact with the world compels my brain to respond. This unending process improves the flexibility of my brain, which ultimately strengthens me.

Accompanying this cognitive growth, I realize the benefits of my decision to pursue a graduate degree in Disability Studies daily. Chief among the gifts: very significant enhancement of cognitive abilities, which in turn bolsters my emotional stability; improvement of my expression of humanity for others by learning the history of disabled people; recognition of social and environmental barriers that limit individuals and thereby society; development of marketable skills in order to ultimately survive; Disability Studies concepts and paradigms became lenses through which I now interpret and interact with society; and most significantly, personal acceptance of my identity as a disabled person. These elements combine every day as I process and interact with my surroundings, leading me to advocate the improvement of the lives of individuals, and to alter society from the empowered organizations I now serve. My life since the accident follows the pattern of the quest narrative Arthur Frank describes (1995, p. 115). As evidenced by the positive aspects of survival and living with multiple disabilities, combined with the awareness gained as I pursued a graduate degree in Disability Studies, made available requisite skills to recognize, interact, and respond to the world I encounter.

In summation, the crucible that graduate school became for me, in the end proved fertile ground for my new disabled identity to find foothold, grow, reconnect with others, reintegrate back into the larger world, and continues to drive my efforts to contribute to creation of inclusive societies. In closing, this statement seems to contradict previous negative descriptions I have made regarding my life following the severe traumatic brain injury I acquired; but the difficult adjustments I've made on this side of accident, trauma, injury, coma, MRSA, amnesia, awakening, recovering, and integrating back into society, result with me happier, stronger, and a better person, grateful for lessons learned about this precious life.

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## Strategies to Create a Culturally Responsive Learning Environment

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**Abstract:** This article is based on the workshop *Keeping it Real: Illusions of Equality and Justice on College Campuses*, presented at the 31<sup>st</sup> Annual Pacific Rim International Conference on Disability and Diversity. Lived experiences provide evidence that despite increased dialogue and numerous initiatives undertaken, both students and faculty from culturally diverse populations face discrimination in academic settings.

**Keywords:** social justice, racial microaggressions, disability studies

### Overview of the Issue

Professionals from various practice disciplines, (i.e., mental health counseling, public health, rehabilitation counseling, social work, and criminal justice) espouse the need for cultural competence in order to provide effective services to diverse populations (Bemak, Chung, Talleyrand, Jones, & Daquin, 2011; Cushman, Delva, Franks, Jimenez-Bautista, Moon-Howard, Glover, & Begg, 2015; Matteliano, & Stone, 2014; Nadan & Ben-Ari, 2013; Wood, 2013). In fact, several counselor education and psychology training programs across the nation have infused cultural and social justice perspectives throughout the curriculum that influence future practitioners' ethical decision-making (Pack-Brown, Thomas, & Seymour, 2008; Zalaquett, Foley, Tillotson, Dinsmore, & Hof, 2008). Training strategies have typically combined theory with practice and focused on the acquisition of specific awareness, knowledge and skills posited to enhance understanding of culturally different clients (e.g., those with racial/ethnic, disability, gender, sexual orientation, language and religious differences). However, despite increased dialogue, revised accreditation standards, and numerous initiatives, it appears that culturally diverse students and even faculty still face acts of racism in the academy. These contemporary acts of racism, known as microaggressions, are defined as "brief, commonplace daily verbal, behavioral, or environmental indignities, whether intentional or unintentional, that communicate hostile derogatory, or negative racial slights and insults to the target person or group" (Sue et al., 2007, p. 273). These targeted groups also include persons with disabilities.

While disability is not analogous with race or ethnicity, it appears that racial/ethnic group membership is related to disability. Specifically, the latest U.S. Census reports, African Americans account for 22.2% of persons with disabilities; Hispanic/Latino Americans 17.8%, Native Americans/American Indians 16.8%, and Asian Americans 14.5%. Additionally both culturally different groups share many common experiences. Specifically, persons with disabilities and other culturally different groups have a mutual history of systemic oppression, inequality, and bigotry. Their identities, value systems, and beliefs have all been historically determined by the majority group (Olkin, 2002). Therefore, the convergence of race/ethnicity and disability cannot be ignored. The workshop, *Keeping it Real: Illusions of Equality and Justice on College Campuses*, presented at the 31<sup>st</sup> Annual Pacific Rim International Conference on Disability and Diversity, provided evidence that culturally responsive training must include a discussion about disabilities with regard to working with students and faculty from diverse cultural backgrounds.

Access and opportunity enables increasing numbers of students and faculty from culturally diverse groups, to pursue higher education and employment in the academy. However, this has not necessarily translated into welcoming, non-biased attitudes from the majority of students and faculty members. Many individuals from culturally diverse groups continue to experience the negative consequences of contemporary expressions of verbal, behavioral or environmental indignities.

#### Evidence from the Film, *If These Halls Could Talk*

The documentary film, *If These Halls Could Talk*, showcases eleven college students who intimately share their lived experiences of cultural diversity on college campuses across the country. These discussions take place under the guidance of Lee Mun Wah, who acts as both facilitator and director of the film. As demonstrated in the workshop, the film is used as a stimulus for needed but often delayed dialogues about cultural diversity and disability on college campuses.

Documentary participants' anecdotes underscore the negative consequences of microaggressions. As previously mentioned, microaggressions are acts of intentional or unintentional discrimination based on one's group membership. Counseling psychologist Derald Sue further identified three forms of microaggressions: (1) microassaults, as explicit verbal or normal attacks meant to hurt the intended victim through name-calling, avoidant behavior, or purposeful discriminatory actions; (2) microinsults as communications that convey rudeness and insensitivity and demean a person's racial heritage or identity, and (3) microinvalidations as communications that exclude, negate or nullify the psychological reality of a culturally different person (Sue et al., 2007). Participants in the documentary supported how the chilly climate of the academy has been equally discouraging for them as students. For example, students who identified as culturally different generally had the shared experience of being ostracized from their student bodies at large. This parallels students with disabilities' own experiences, who because of their differences are often socially isolated in higher education (Liasidou, 2014).

Students with disabilities and acquired conditions fare no better in the academy than those who were assessed by race/ethnicity alone. In fact, the chilly, unwelcoming climate for these students is often expressed with devaluation, doubt, and exclusion. Examples of devaluation may be manifested with faculty overlooking, rather than correcting students' mistakes and encouraging students to switch to less rigorous majors. Expectations may be lowered, sending students the message that they don't need to do much to "get by." Success may be met with suspicion. Exclusion is common for students with disabilities who are typically separated from their able-bodied peers when utilizing support services (Liasidou, 2014). This exclusion causes these students to be singled out and reinforces the stereotype of neediness among persons with disabilities. These actions not only serve to erode students' self-esteem and define them as second-class citizens but also contribute to the system of differential treatment, disempowerment, and marginalization which often operates in majority classrooms (Hutcheon & Wolbring, 2012; Liasidou, 2014).

In the film one White male student who was HIV positive faced prejudice because of his disability status. His experience of discrimination based solely on a biological factor demonstrates the similar experiences of bigotry often experienced by people of color. This student was asked to describe his experiences of being discriminated against and not having the same amount of privilege that he had prior to his disability status. The student shared that he now knows what it is like to be judged even before people get to know him. This reflects similarities in the majority culture of able-bodied individuals and how that group may take for granted the benefits and rights that come along with the “able” classification. As with race/ethnicity, being in the majority in-group provides access and resources that may not be appreciated until that membership is compromised.

One student, who identified as an Italian woman, admitted that because the color of her skin is white, she usually did not have any trouble on campus. In effect, because she passes for “White” she does not feel racism on a daily basis. It is also important to note that another student in the documentary admitted that rather than deal with the retaliation that is associated with claiming one’s indigenous heritage, she chose to identify with only the Scotch-Irish part of her family, while concealing parts of her ethnic heritage. These examples mirror the experiences of people with invisible disabilities who often choose to keep their disability hidden rather than face the stigma that accompanies the label of being disabled (Baldrige & Swift, 2013; Collins & Mowbray, 2005). These secret identities are maintained in order to avoid being treated differently or negatively by their peers from the majority group.

The facilitator and director of the documentary, Lee Mun Wah, also shared his own experiences of cultural diversity with the group and charged them to imagine the stress, anguish and cognitive dissonance that one must experience from having to always be aware of what he/she says and how he/she may be perceived. One student explained how as one of only two people of color participating in the documentary, he felt uncomfortable. The student explained that people of the majority culture like to assume others should feel comfortable because they, themselves, are comfortable. Again parallels to people with disabilities can be made with regard to others being comfortable. For example, research indicates that service provisions for persons with disabilities are impacted by the level of comfort of the counselor (Friedman, Helm, & Woodman, 2012; O'Brian, Packman, Onslow, & Cream, 2003). As asserted by the student in the documentary, it appears that people of the majority culture do not see the world as it is, but rather as they experience it.

Overall, the documentary provided a platform for a discussion about cultural diversity and disability on college campuses to occur among the film participants and among groups who view the film. While the documentary can be a powerful tool in discussing matters of cultural diversity on college campuses, it has limitations. First, it may be helpful to unpack issues of gender, sexuality, disability, and race/ethnicity. Secondly, there appears to be a lack of practical strategies that rehabilitation counseling educators can employ to increase dialogue about cultural diversity in the academy.

#### Response and Recommendations

In response to the need to provide culturally responsive services to an increasingly growing multicultural population in the United States, the following suggestions have been

gathered based on extant researchers and authors own personal experiences. Educators have called for multicultural competence and social justice initiatives within psychology and counselor education programs. Educators, in particular, are tasked to teach students the requisite knowledge, skills, and abilities to work with culturally and ethnically diverse populations. However, evidence exists that within the very classrooms where multicultural and social justice curriculum is being taught, students and faculty of color still face different and unequal treatment. The shared lived experiences of documentary participants may be instructive to administrators and faculty in higher education to increase awareness and sensitivity regarding the impact of this treatment and modify their behaviors. The following strategies were gleaned from extant research and are offered to change the environment and create a more culturally responsive learning climate:

1. Both students and faculty must understand that not everyone in their program, department, or school is dedicated to creating a culturally responsive learning environment. Students and faculty can take advantage of opportunities within their courses and organizations to promote cultural knowledge acquisition. This can be achieved through classroom activities (e.g. group work, case studies, role plays, class discussions) and community based projects in student organizations which focus on issues related to serving culturally diverse groups.
2. As demonstrated in the documentary, *If These Halls Could Talk*, intimate encounters with culturally diverse people can lead to more positive attitudes towards people of color and people with disabilities. As such, service learning provides students with hands-on experiences working one-on-one with culturally diverse people. Students are afforded the ability to transform multicultural and disability knowledge and skills acquired from courses into practice within the community (Boston, 2009). Faculty is encouraged to add experiential learning experiences throughout the course curriculum. Partnerships with regional and local community agencies will provide students with exposure to real-world multicultural counseling encounters throughout their program instead of only during the standard practicum and internships placements.
3. Don't take for granted that culturally diverse students are culturally competent. Research conducted in the area of multicultural counseling competence indicates that students' ethnicity is not a good predictor of multicultural knowledge (Boston, 2009; Donnell, 2008; Holcomb-McCoy & Meyers, 1999). Though students of color may have a greater interest in multicultural issues, they may not necessarily be more knowledgeable about these matters. Therefore, faculty must assume that all students come to the classroom with some understanding and work towards increasing their students' knowledge of multicultural counseling.
4. Faculty should lead students in discussions about the media's portrayal of culturally diverse groups and how these portrayals impact attitudes, values, and self-esteem of students. Faculty can help students better understand how the media influences how we think about race/ethnicity, disability, gender, sexual orientation, language, and religious differences through the images displayed through mass media (Littlefield, 2008). Discussions should promote exploration of personal biases regarding race, gender,

disability, privilege, oppression, and socioeconomic status of individuals and how these factors will shape students' role as a counselor.

5. Faculty should engage in deep self-reflection of their own attitudes, beliefs, and biases about those who are culturally different, including those with racial/ethnic, disability, gender, sexual orientation, language, and religious differences. Awareness will create an opportunity to challenge oneself and lead to better outcomes in creating a culturally responsive learning environment for all.

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## Using the International Classification of Functioning, Disability and Health (ICF) to Improve Understanding of Disability and Functioning

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**Abstract:** The International Classification of Functioning, Disability and Health (ICF) has been increasingly recognized for facilitating improved statistical data collection, social policy development, and clinical research in disability and health sectors. Many practitioners working in disability and health-related fields as well as government officials and policymakers in multiple countries consider it to be a useful system to better situate disability, health, and functioning. Positively, the ICF's biopsychosocial framework recognizes disability and functioning as the dynamic individual and environment interaction, promoting a more realistic perspective for social workers and related practice-oriented professions such as occupational therapy and speech language pathology. Despite being an integrative model of disability, there are some problematic aspects within the ICF classification that have been raised specifically by advocates within the disability community and educators in disability studies. This article describes the ICF system, its utility, and its overall strengths and weaknesses in promoting a better understanding of disability and functioning.

**Key words:** WHO, disability classification, social model of disability

### Introduction

In 2001 the World Health Organization (WHO) published its International Classification of Functioning, Disability and Health (ICF) that focuses upon health and health related domains. After seven years of testing for cross-cultural applicability in over 50 countries, the ICF was finalized and then endorsed by 191 countries of the 54<sup>th</sup> World Health Assembly. It is currently available in several official WHO languages including Chinese, English, French, Russian and Spanish; however, it has been translated into over 30 more languages. Diverse stakeholders influenced its overall development including persons with disabilities, professionals across disciplines, researchers, statisticians, educators, insurers, and government officials.

Currently, the multi-purpose ICF is being implemented throughout the world in policy, research, education, and clinical practice. For example, in the United States the American Speech-Language-Hearing Association (ASHA) has used the ICF as the organizing framework for its "person-centered focus on function" series that cover health conditions such as traumatic brain injury, dementia, and several hearing loss and falls (ASHA, 2015). In Sweden the ICF has been demonstrated to be useful in the electronic health record for social service management process among the elderly population (Almborg & Welmer, 2012). And ICF terminology has been incorporated into Japan's comprehensive rehabilitation planning form, a required document for billing of rehabilitation services (Threats, 2015).

Moreover, the ICF has significant potential to become the common global framework for organizing and communicating information on human functioning and disability (WHO, 2001). First, the National Committee on Vital and Health Statistics (2003) recognized the ICF as the

only viable candidate for classifying functional status in clinical and administrative records. Secondly, the classification covers a wide spectrum of life domains, which makes it conducive to use across sectors including education, employment, health care, housing, and social services. Finally, a greater number of decision-makers consider the ICF to be the only valid and reliable standard available for worldwide disability data collection and management (Bickenbach, 2011). For example, the United Nations in its *Guidelines and Principles for the Development of Disability Statistics* (2002) recommended to countries to use the ICF in disability measurement as a basis for the definition of the population with disabilities. In the recently published World Report on Disability (2011), the ICF is used extensively and endorsed by not only the World Health Organization but also the World Bank.

### The ICF Model or Framework

Within the ICF framework and classification there are both individual and environmental factors, reflecting the increased shift in viewing disability and functioning as the interaction of an individual in his/her unique environment (Bagnato et al., 2011). The National Institute on Disability and Rehabilitation Research (NIDRR) first adopted this new paradigm in its long-range plan in the late 1990s and early 2000s. Sharing this same viewpoint, the Institute of Medicine's report *Disability in America* (IOM, 1991) defined disability as "a gap between a person's capacities and the demands of relevant, socially defined roles and tasks in a particular physical and social environment."

As a positive theoretical step forward, the World Health Organization recognized the incompleteness of two primary models historically referenced in ongoing disability discourse – namely, the medical model (which views disability as part of the person caused by disease, trauma, or other health/mental health condition) and the social model (which emphasizes and politicizes how the environment creates disabling conditions for persons). Bridging these two key disability theories, the WHO developed an integrated model of disability for the ICF system called the "biopsychosocial" model, which describes how people actually live with their health condition influenced by social and environmental components (Bickenbach, Chatterji, Badley, & Ustun, 1999; World Health Organization, 2001).

The ICF model asserts that disability frequently starts with some health condition that likely leads to impairments, which in turn contributes to activity limitations and participation restrictions all influenced by contextual factors (environmental and personal factors). Figure 1 depicts the ICF conceptual framework and the basis for its overall classification system. The ICF is organized into multiple domains expressed along a continuum of functioning to disability. Functioning is the umbrella term for all body functions and structures, activities and participation (execution of a task or activity by an individual) and participation (involvement in a life situation). Disability is the umbrella term for impairments (loss or abnormality of body function or structure), activity limitations (difficulties individuals may have in executing activities), and participation restrictions (problems individuals may experience in involvement in life situations).

### Key ICF Components

The ICF classification is divided into chapters addressing approximately 484 body functions, 294 body structures, 382 activities and participation items, and 253 environmental factors. There are domains encompassing all body functions and structures (see Table 1), ranging from mental functions to voice and speech functions as well as structures for movement and skin related structures. For the Activities and Participation component, there are nine primary domains including: (1) Learning & Applying Knowledge, (2) General Tasks and Demands, (3) Communication, (4) Movement, (5) Self Care, (6) Domestic Life Areas, (7) Interpersonal Interactions, (8) Major Life Areas, and (9) Community, Social & Civic Life.

Contextual factors are recognized as an important component in the ICF in terms of environmental factors and personal factors. While there is a section on the environment, personal factors were not included in the classification due to wide variability globally. Personal factors include variables such as age, race, gender, education, social background, psychological assets, lifestyle habits, and upbringing (WHO, 2001). This has been identified as a weakness of the classification and an area for future work, possibly another main section of the ICF.

For the environment section, there are five main chapters including: (1) Products and technology, (2) Natural environment and human made changes to the environment, (3) Support and relationships, (4) Attitudes, and (5) Services, systems and policies. Certainly, the inclusion of an entire section on the environment is more aligned with a social model of disability and makes the ICF more attractive to those who support such a social model. Interestingly, qualifiers in the ICF allow the simultaneous identification of both barriers and facilitators within a person's environmental context. Being able to identify and increase the positive facilitators while decreasing or removing the negative barriers is critical for facilitating change in the lives of persons with disabilities and their families. Environmental changes include such aspects as legislative reform, building modification, capacity building, and technological developments.

### Positive Changes from ICIDH to ICF

Unlike its predecessor, the International Classification of Impairments, Disabilities and Handicaps or ICIDH (WHO, 1980), which received much criticism by the disability community, the ICF reflects multiple changes in line with more recent paradigm shifts around the meaning of functioning and disability as previously discussed. The ICIDH was considered too linear in nature where the health condition automatically leads to impairments, disability, and handicaps without variation. It is well established that persons with disabilities may function without difficulty in certain life domains due to assistive technology, personal support, and other factors. More positively, the ICF presents an interactive, dynamic framework of disability and functioning that accounts for such realistic variation in the lived experience among persons with disabilities. And neutral terminology has been used in the ICF unlike the previous version that included negative terms such as "handicap."

In addition, the ICIDH emphasized heavily the individual as the locus of intervention without equal emphasis on the environment as the target for change. Now, the ICF views disability beyond a medical or biological dysfunction and recognizes the social aspects

contributing to disability (Van Hove et al., 2012). By including policies, programs and services in its environmental section within the classification, the ICF provides a mechanism to identify strategies for intervening at an organizational or systems level and removing constraints or barriers that disabled individuals in their communities (Saleeby, 2007).

As another positive development, the ICF also addresses the needs of children and youth through the ICF-CY, or the International Classification of Functioning, Disability and Health for Children and Youth. Published by the World Health Organization in 2007, this version addresses developmental aspects of childhood from birth to age 17 with specialized domains such as play. Due to its comprehensive nature addressing children and youth issues, the ICF-CY is particularly useful to understand functioning in children and youth and facilitates the identification of potential interventions (Simeonsson, Leonardi, Lollar, Bjorck-Akesson, Hollenweger & Martinuzzi, 2003). Like the ICF, the ICF-CY recognizes the impact of the environment (social and physical factors) on individual functioning and disability in conjunction with a person's health condition. This supports a more social model of disability, which considers disability the result of society, rather than a person's impairment or difference.

#### Increasing Support of the ICF

As the result of these and other changes, the ICF has increasingly become more favorable among persons with disabilities, family members of persons with disabilities, and professionals with and without disabilities working in disability and health related fields. In fact, many persons with disabilities as well as representatives from disability organizations including Disabled Peoples International, European Disability Forum, and Inclusion International influenced the ICF development process.

As indicated by Rachel Hurst (2003) in her capacity as the representative of the World Council of Disabled Peoples' International (DPI) to the ICIDH revision process:

“Use of the environmental factors within the ICF will ensure appropriate policies, systems and services for health care and support, provide measurable indicators for health status and sustainable development and underpin the recognition that disability is a human rights issue.”

Positively, the ICF has been officially accepted as a social classification by the United Nations and it has been recommended for use as a standard data collection mechanism to help enforce the monitoring requirement in conjunction with the CRPD (Bickenbach, 2011). Although the ICF is not explicitly mentioned in both the Standard Rules on the Equalization of Opportunities for Persons with Disabilities and the Convention on the Rights of Persons with Disabilities, its conceptual foundation is reflected in these key United Nations documents (Cieza & Stucki, 2013). Specifically, the UN recognizes disability as the dynamic interaction of the person within his or her environmental context. In the CRPD Preamble, disability is defined as the “interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others.”

### Why Use the ICF?

With its emphasis upon functional status, the ICF can provide more meaning beyond diagnosis alone about the actual experiences of persons with various health conditions. Consider the impact on the person who exhibits symptoms but cannot get treatment due to the lack of formalized diagnosis. For most insurance companies, a diagnosis is a requirement to access coverage for necessary health care, treatment, and social services. This is a drawback in using a diagnosis-based reimbursement system. On the contrary a system that takes into account functional status information would determine eligibility for services based on documented limitations in a person's activities or restrictions in his/her participation. The impact on a person's life is a more realistic gauge for generating benefit determination.

The ICF provides a mechanism to account for these situations that are becoming more and more common in clinical practice. Not only for social workers, but related health professionals experience issues where diagnosis is not possible or not substantiated; yet, the person must receive some immediate intervention, rehabilitation, or treatment. The biopsychosocial model of the ICF broadens the perspective of disability and allows the examination of individual, environmental, medical, and social influences on functioning and disability to be examined (Kozstajnsek, 2011).

Assessment that is multi-dimensional including information about the person (medical and social histories) as well as the environments (home, work, school, and community) is reflected in the ICF. Although the ICF itself is not an assessment tool, there are instruments based on the ICF or cross-walked to the ICF. And the ICF allows for a description of functioning in clinical (standardized) and everyday (realistic) environments, which is extremely important for all persons with or without disabilities.

Furthermore, there is a need for reliable and comparable data on the health status of persons along with functioning and disability, which the ICF classification provides. The ICF provides a mechanism to collect disability data at national and international levels to better inform policy development. Not only must data collection be possible across various countries, but information must be collected and comparable across disciplines and population groups. The ICF conceptual framework has been recommended as the basis for measuring disability in the United Nations Statistics Division's publication, entitled "Guidelines and Principles for the Development of Disability Statistics" (United Nations, 2002). According to Jelsma (2009), the ICF has already made a major impact on the way in which data concerning disability are conceptualized, collected and processed."

### Conclusion

With its comprehensive system including the environment, the ICF provides a conceptual framework and classification for understanding both the causes and consequences of disability on the functioning of individuals. The nature of this information is extremely useful in developing appropriate mechanisms to reduce or alleviate barriers to functioning (Saleeby, 2011). For example, a comprehensive assessment based on the ICF can be used to identify key information about a person's life including his or her body functions and structures, activities and participation, and environmental barriers and facilitators. Information that is identified

through the process can be used immediately to initiate intervention or treatment regardless of whether a formal diagnosis has been made by a relevant health professional. Therefore, the ICF as a comprehensive, integrated model holds great potential for promoting individual and social change (Howard, Nieuwenhuijsen, & Saleeby, 2008).

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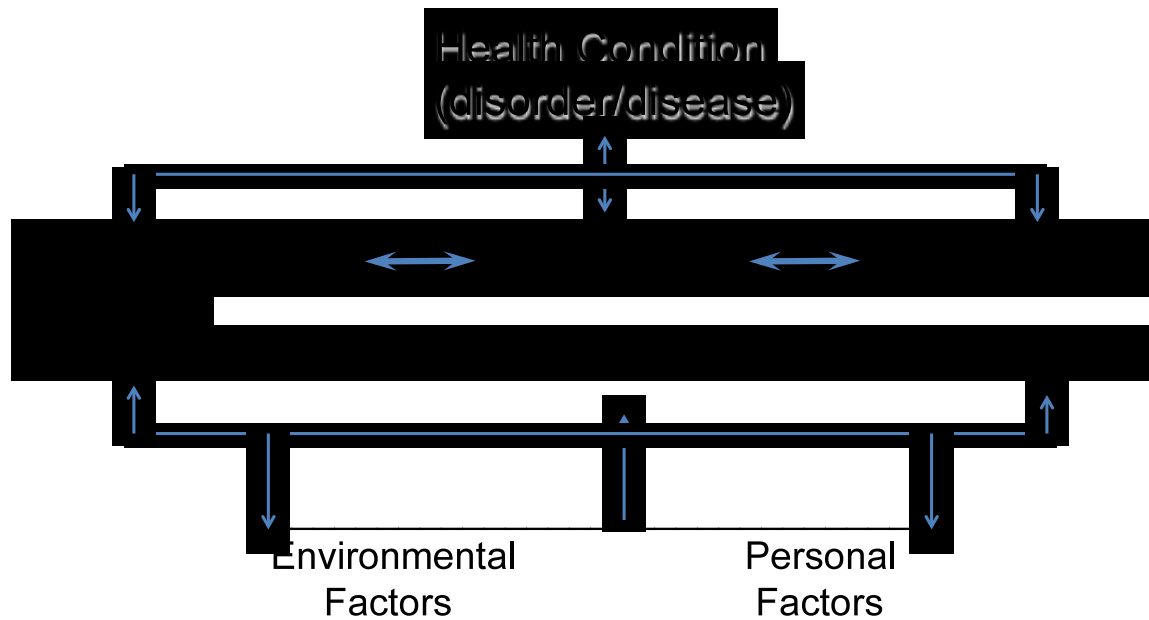
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# ICF CONCEPTUAL FRAMEWORK



*Figure 3 The ICF Conceptual Framework Health Condition; Body Function/Structure; Activities; Participation; Environmental & Personal Factors*

Figure 1. ICF Conceptual Framework (WHO, 2001)

Table 1. ICF Body Functions and Structures

Mental Functions	Structures of the Nervous System
Sensory Functions and Pain	The Eye, Ear and Related Structures
Voice and Speech Functions	Structures involved in Voice and Speech
Functions of the Cardiovascular, Haematological, Immunological and Respiratory Systems	Structure of the Cardiovascular, Immunological and Respiratory Systems
Functions of the Digestive, Metabolic, Endocrine Systems	Structures Related to the Digestive, Metabolic and Endocrine Systems
Genitourinary and Reproductive Functions	Structure Related to Genitourinary and Reproductive Systems
Neuromusculoskeletal and Movement-Related Functions	Structures Related to Movement
Functions of the Skin and Related Structures	Skin and Related Structures

Summary of Table 1 entitled *Body Functions and Structures*. This table has two columns. The column on the left in descending order reads: Mental functions; sensory functions and pain; voice and speech functions; functions of the cardiovascular, hematological, immunological and respiratory systems; functions of the digestive, metabolic, endocrine systems; genitourinary and reproductive functions; neuromusculoskeletal and movement-related functions; functions of the skin and related structures. The column on the right lists: structures of the nervous system, the eye, ear, and related structures; structures involved in voice and speech; structure of the cardiovascular immunological and respiratory systems; structures related to the digestive metabolic and endocrine systems; structure related to genitourinary and reproductive systems; structures related to movement; skin and related structures.

## Creative Works

### Devastate/Celebrate

Steve E. Brown, PhD

**Abstract:** A poem written for the 2011 Abled Hawaii Artists celebration of the signing anniversary of the Americans with Disabilities Act, which fits well with the presentation, “Power, Pride and the Road to Freedom: What Can We Say about the Americans with Disabilities Act?” made at the 2015 Pacific Rim Conference.

**Keywords:** Americans with Disabilities Act, Abled Hawaii Artists, Disability culture

In Hawaii, for over a decade now, the premier--usually the only celebration of the signing anniversary of the Americans [with Disabilities Act has been](http://www.cds.hawaii.edu/aha) Abled Hawaii Artists--on the Big Island of Hawaii for the past eight years ([www.cds.hawaii.edu/aha](http://www.cds.hawaii.edu/aha)). The event began in 2003 as a team project of a course I co-taught and for many years I served as an advisor for the event. As a result, in 2011, I had an opportunity to travel to Hilo and be a presenting artist. I chose to debut my call-response poem, “Devastate/Celebrate.”

At the 2015 Pacific Rim Conference on Disability and Diversity, I presented “Power, Pride and the Road to Freedom: What Can We Say about the Americans with Disabilities Act?” as part of the “Disability Studies” topic area. The PowerPoint from that presentation is available at: <http://www.slideshare.net/SteveBrown17/power-pride-andtheroadtofreedom5102015>.

While I did not read the poem at the conference, I believe it fits well with both the topic area, the 25<sup>th</sup> anniversary celebrations of the ADA and this forum.

Please enjoy the poem below.

### Devastate/Celebrate

Hello, my name is Steve

And yours?

Hello....

Have you ever been told you couldn't vote?

I have!

Have you ever been told you couldn't work?

I have!

Have you ever been told you couldn't play?

I have!

Have you ever been told you couldn't buy insurance?

I have!

Have you ever been told you couldn't live where you wanted?

I have!

Have you ever been told you couldn't love?

I have!

Have you ever been told you couldn't live?

I have!

My brothers and sisters and I have been labeled and re-labeled. We've been called:

Cripple

Handicap

Unable

Freak

Deformed

Spaz

Retard

Tragic but brave

Useless eater

We've been incarcerated, killed, maimed, and experimented on.

Devastated.

But!... We've also

Survived centuries of isolation and abuse

Claimed our words: disability, cripp, gimp.

Written discrimination diaries

To demand our rights!

Taken over buildings and courthouses

To demand our rights!

Marched for the passage of laws

To demand our rights!

Climbed and crawled the steps of the Capitol

To demand our rights!

Sung our songs on the streets where we blocked buses and buildings

To demand our rights!

Twenty-one years ago Congress passed and the President of the USA signed the

Americans with Disabilities Act

After we marched in the streets

Filled our diaries

Crawled up the steps of the Capitol

Testified:

A young girl's story of being barred from a movie theater shattered Beltway hearts.

Congress passed a law

The Americans with Disabilities Act

Saying we had a right to vote, to work, to play, to live, to love.

And we have a right, a time, today, to celebrate our victories.

To cheer

Our heroes—there are so many—here are some of mine:

Ed Roberts—a newspaper called him a “helpless cripple.” I call him a “wheelchair genius,” who broke college barriers in 1962 in Berkeley;

Helen Kutz, first leader of Oklahoma disability rights, my mentor, my friend, compassionate and provocative;

Justin Dart, today known as the father of the ADA, collector of discrimination diaries, and pioneer of “Justice for All;”

Laura Hershey reminded us “You Get Proud by Practicing.”

Paul Longmore re-discovered the League of the Physically Handicapped,” a piece of our forgotten history--1930s New Deal protestors;

Judy Heumann, first lady of the disability rights movement, once told by New York City she couldn’t teach because her wheelchair was a fire hazard. Today, she works for the Department of State and has traveled the world over.

Leroy Moore, creator of Krip Hop, emcee with a disability;

Ron Mace, architect, created the concept and coined the term, Universal Design; and

Sarah Triano, co-founder of the National Disabled Student Union and the longest ongoing Disability Pride Parade, in Chicago, and another in San Jose.

Too many more to name, to cheer, to celebrate,

But celebrate we must. Emma Goldman declared:

“If I can’t dance, I don’t want to be part of your revolution.”

And we are dancing today!

We are showing off our art

And we are dancing today!

We are hundreds of millions strong

And we are dancing today!

We are sharing our stories

And we are dancing today!

We are chanting our own tunes

And we are dancing today!

We are claiming our spaces

And we are dancing today!

We are performing our lives

And we are dancing today!

We are having AHA moments

And we are dancing today!

We are dancing today!

Written by  
Steven E. Brown  
and read at Abled Hawai'i Artists (AHA), Hilo, Hawai'i, July 23, 2011  
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**Historian Steven E. Brown** is a retired Professor and Disabilities Scholar, Center on Disability Studies (CDS), University of Hawaii (currently Affiliate Faculty); Co-Founder of the Institute on Disability Culture, and 2015 Diversity and Inclusion Fellow for the Association of University Centers on Excellence in Disabilities (AUCD) Diversity and Inclusion Initiative. Brown, a former editor of the *Review of Disability Studies*, has published many articles about disability rights and disability culture and is a national and international speaker. His books include *Movie Stars and Sensuous Scars: Essays on the Journey from Disability Shame to Disability Pride* and *Surprised to be Standing: A Spiritual Journey*. Brown relocated to the California Bay Area in 2014, where he continues to write, advocate, and teach. A Middle Grade biography, *Ed Roberts: Wheelchair Genius*, will be published in 2015. Brown blogs at <http://www.instituteondisabilityculture.org/manifesto> and is on Twitter @disculture.



## Multimedia

### The Spoken Word and Emotion in Communication

Karen Lee Roberts, Australia

**Abstract:** The spoken word, and the emotional qualities of communication within this have always been paramount in my life. I put this down to two vital points: my artistic ability, and my disability. I am an artist first, a children's book author and poet, a singer and actor, writing much of my material myself; songs, children's rhymes for recitation and plays. This is my love and passion, and it keeps me focused and well, despite my disability. But it is my disability that enables me to express myself so well, and allows me to be so passionate.

**Key words:** Art, performance, self-expression, advocacy, disability

Click here to view the You Tube video and transcript: <http://www.rds.hawaii.edu/its-not-easy-being-green/>

#### The Spoken Word and Emotion in Communication

The spoken word, and the emotional qualities of communication that characterize spoken word, have always been paramount in my life. I understand this as informed by my artistic ability, and my disability. I am not bound by my disability, but rather I focus on the positive attributes I possess. I see myself as an artist first, a children's book author and poet, a singer and actor, writing much of my material myself: songs, children's rhymes for recitation and plays. This is my love and passion, and it keeps me focused and well. But it is my disability that enables me to express myself so well, and allows me to be so passionate. You see, I have bipolar 1 disorder. This is a mental illness manifesting itself in the form of mood symptoms, manic and depressive, to be exact. It involves experiences of great peaks and troughs in temperament, and can also include psychotic symptoms. The highs and lows I have encountered throughout my life have been accompanied by a myriad of emotions that the spoken word has helped me to express. I started writing and singing songs when I was five years old, and reciting poetry about the same age. I have gone on to perform jazz and blues around the world, original songs, and cabaret shows; all of which have provided important creative outlets to express myself. I must communicate my emotions to deal with the disorder. I most often do this through my art form, but sometimes it is just in conversation. My father teases me, saying I use my hands too much when I speak. I say it's just the Mediterranean in me...but then again, I'm only half Greek, so I suppose I should only be using one hand, shouldn't I?

Whatever the case, I am extremely expressive and emotional, and this is communicated through spoken word, in everyday situations, and in my professional art. This may be an amalgamation of being talented, bipolar and Mediterranean, perhaps! When people listen to the words of my songs, they often comment, "I can really relate to that", or, "You've made me realize something". Although it is not the only, nor the best medium of communication, the spoken word can be powerful. It can move people with emotion. Since I've experienced disability, I've needed a way to express the emotions I feel, and to touch other people with my

journey. My music and poetry, and most recently a play I've written, seemed the best way to express myself and entertain others at the same time.

After recovering from 20 years of severe episodes of bipolar disorder, I wanted to express my emotional journey of finding my place in this world. The road to stability can be difficult to reach, and hard to find if you don't know what steps to take. What should one do? Without the appropriate guidance, it is easy to get lost along the way. I wanted to help others, to reach out to both fellow sufferers and those in the general public who might not understand the experience of mental illness, and what mental wellness means within the context of this experience.

But how to communicate this? For me the answer was obvious. There is no more powerful way to reach people than through theatre or music. Getting an audience to laugh or to cry, moving them, will evoke a response that simply giving stale information will not. So I embarked on the process of writing a play, a cabaret, about my experiences of maintaining wellness with a mental illness. The cabaret is called "It's Not Easy Being Green", was a reflection on the struggles that can shape experiences of mental illness. It was performed in June 2015 at Queensland Theatre Company's Billy Brown studios in Australia, for the Undercover Artists Festival. It was an opportunity for people from all different areas of society to view the show at the festival, and gain insight from its content. This work demonstrated how spoken word and emotion in communication can have a positive effect in both educating and entertaining people on important self and social issues. It was funded by Queensland's Access Arts Incorporated, a disability organization for the arts, and the show itself was directed by leading Queensland actor/ director Sandro Colarelli. I performed in the cabaret with vision impaired pianist, Jeff Usher.

The message that is communicated by the text in the play is one I wish to send to those both directly affected by mental illness and those in the general public. All this is done by scenes filled with some sad and happy scenes and scenarios...some even a bit sexy and saucy! Like the seduction scene, where I go to bed with an invisible Internet date...don't know how he unhooks my bra! With a lot of paraphernalia, I can tell you! Each story in the play has an emotional reflection, and communicates this to try and get the point across about contentious issues related to mental health and illness with the spoken word, which is accomplished by relating various poignant points in the text of the show.

I wrote most of the music in the show. Writing songs offers another way to communicate with spoken word, bringing important messages of social and personal content in the lyrics. Music translates beautifully to tell stories, captivate feelings, and just simply let things out. In my cabaret, each song reflects a poignant point in the play, and the power of emotion evoked by these tunes instills meaning toward what is being portrayed.

I would now like to discuss the importance of emotion and communication as spoken word in terms of youth in today's society, and also the vital role that spoken word plays in emotion and communication for people experiencing disability. Theatre and music as spoken word provide an important avenue for self-expression, and when one experiences a disability, that expression becomes even more poignant. The words in a song or in a play are full of meaning and depth of content, and relay stories and emotion that can have a profound impact on

audiences. Even the expression for those with a disability who are unable to speak can be executed using words to communicate their emotions effectively, through speech translators or sign language. Words are a powerful tool of advocacy, release and therapy, which make it possible to communicate lived experiences on an emotional level. The spoken word, particularly in a creative context, such as music and theatre, allows for this expression of self that gives people an outlet to release feelings they may have about life, society or themselves. This is so important for those experiencing disability, as in many cases we need to express much more than the average non-disabled person. People experiencing disability can be extremely artistic also, and words, and indeed the spoken word, can be an excellent way to outlet that creativity. Occupational therapy is often used in psychiatric hospitals and disability units these days, with theatre and music as integral parts of their programs. Spoken word is a huge part of the accessibility to these artistic outlets, and allows people the freedom to express themselves vocally.

The organization I am a member of named *Access Arts* was created for people experiencing disability and/or disadvantage. Through this organization, I was involved in a project called "Sound Circles" to encourage people to express themselves vocally. Through spoken word and sound, they would relate meaning in their life about what they were experiencing every day, their thoughts, feelings and ideas and what was important to them. Spoken word served as a vehicle to communicate emotion. Sound Circles was a part of World Expo 88 and Access Arts toured it to Japan. We traveled from regional Queensland right up to far north Queensland in Cairns doing workshops involving people experiencing disability. It gave these people freedom to express the truths and hurts and joys and pains and wonders of life. It brought people together from all different communities in spoken word to communicate emotion.

You begin with a single sound. This develops into a word. This is repeated, turning into a series of words that develop into a sentence. From this you build into a song, or a poem or a chant. Movement is incorporated into the sounds intoned by the words, and a whole theatrical piece is structured. But it is organic and free. Freedom is essential, as is a sense of unity. Creating words crafted into an ensemble of soulful musical sounds, or sensitive rhymes or rhythmic beats. One time we developed an entire film called "Douge's Not So Peaceful Dream" which we acted out and staged. This amalgamation of personalities and different perspectives in voice was a wonderful experience for all involved, and gave people the opportunity to put concepts of emotion into words.

Another chance I had to utilize the spoken word and emotion in communication was through music therapy with the Cerebral Palsy League of Australia. I worked at Springfield Space, a day care centre, and did interactive karaoke sessions with the clients there. Through the power of music and the expression of self with spoken word in this form, people were able to communicate their feelings and inner passions with songs. Some people who barely spoke much at all in everyday situations would unleash in a song and just let go. The emotion conversed through the connection of feeling the music and words together was incredible...they just transformed into diligent linguists, masters of the spoken word. The therapy was incredibly successful in drawing people out of themselves and into a relationship with others. It brought down barriers, and built up interactions within the group.

We also filmed at the Cerebral Palsy League, making disability action awareness videos for internal distribution. These followed the Disability Awareness Standards, and the clients acted out the procedures. They loved using dramatic situations to depict the different scenarios-again, spoken word and emotion in communication used in a theatrical sense. They were expressive and generous in showing their feelings, and this gave tremendous weight to the film.

I was also asked to represent Australia at the Wataboshi Festival in Johor Baru in Malaysia in 2007 for a coming together of all persons disabled to perform music together in celebration. This communication of emotion through spoken word was extraordinary as language barriers were transgressed and cultures were brought together in an amalgamation of song. I sang my original song, "Society's Blues", a social statement about the world we are living in. It means a great deal to me, this piece, and stirs up enormous feeling within. When I sing it, this impacts on my performance, and this is translated to the audience. At Wataboshi, all the songs performed were originals of incredible talent by artists experiencing disability who had valuable life stories to tell. The festival provided insight into other creative people's outlets of expression and also the different ways cultures feature music. It was an amazing experience for me.

In this changing world of technology, so much social contact is lost through social media and smart devices. People don't connect so much with each other; they text the spoken word and the emotional meaning gets lost in the message; they face time each other and don't speak in real company; emails have replaced a coffee down the road; Face book means no one has to meet up in person anymore. The younger generation in particular lives in a virtual world, existing of computers, i-pads and mobile phones. For heaven's sake, they're not even getting up to nooky in person anymore...they're sexting! Now really, where's the fun in that? Two together has GOT to be better than you and your phone...

Off the subject of sex...it always comes up in a speech, doesn't it...and back on track! What is so wonderful about live theatre and music is that people experience a "tactile" appreciation of each other for a set amount of time, enjoying the opportunity to interact together. They feed off each other's emotions as dictated by the performance, and react accordingly. They appreciate what is being presented for its emotional meaning as communicated by the language content, and are moved in a positive or negative manner thus words move them as a whole unit - an audience - they react and applaud and laugh and cry and are affected by their emotions.

In my own experience, working with youth on spoken word and emotion in communication in theater and music is again a powerful tool. In 2013 I wrote two children's plays for the Metro Arts Theatre in Brisbane. The first was called "Maryanne the Chameleon", and was for younger children, around six to twelve years of age. We performed and rehearsed it in a workshop environment, doing a reading of the script and improvisation of the characters. There was also music involved with songs I had written. The play was about difference issues, and war and peace.

The children reacted very strongly to being able to vocalize their views to the content in the play, and to then perform it. They were positive in their responses, interactive, involved and receptive. They understood the messages being conveyed by being associated with the theatrical

piece, and when exposed to the music, became animated with the beat and rhythm and sang along with much enjoyment. Theatre and music as spoken word evoked much emotion in them, and allowed them to communicate these feelings. There were responses of sadness and fear to the aspects of war, happiness and joy to the inclusion facets surrounding the chameleon and her color difference, and understanding traits reflected in their appreciation of the reigning of peace and tolerance that was evident in the moral of the story. All emotion communicated through spoken word, both in dramatic context and in discussion of the text.

The second play I had written was “Casey the Cockatoo” aimed at an older teenage audience. It dealt with issues of aboriginal incarceration and a situation in Australia called the “Stolen Generation”, where young aboriginal children were forcibly removed from their parents and placed in white families for the purposes of assimilation. Some were reduced to slavery. The play was meant to be directed at fueling more serious discussion. The director and I got a group of young actors in to expose them to the material. They absorbed themselves in the text, becoming the characters and being moved by the story. It was about a cockatoo having its chicks taken away from her, and then being caged in a zoo. The power of spoken word brought such emotion to this youth, they came up with an incredible portrayal of the events and depicted scenes from the play in moving and innovative ways. We staged the piece with movement done to the spoken text, and as it was in a poetry form, this became like a rhythmical masterpiece. Original music that I had written accompanied it, and this too added to the performance. All these elements of spoken word reached deeply into the emotions of the actors on stage, and likewise touched audiences in watching.

I am now delivering my cabaret on mental wellness to open the minds of youth to topics that are essential for them to gain insight to, to understand and to broaden their horizons. The music, as well as the theatrical content of the cabaret, brings messages of a lived experience of mental wellness. It encourages prosperity, and trying to find the best possible outcomes of everyday life through communicating emotions, feelings and true to life situations through spoken word.

I have touched on the reasons why theatre and music are vital in the role as spoken word and emotion in communication. They open up avenues of opportunity to access theatre, music and the arts by engaging those experiencing disability and the younger generation allowing them to communicate emotions through spoken word in a variety of ways. This is accomplished by viewing and listening to theatre and music as they are made available; by creating the art forms themselves, and thus contributing to the works being made in society; by encouraging others to do both these activities; by maintaining an appreciation of creativity that allows them to be open to these emotions through spoken word communication for the rest of their lives.

I ask you to engage more in these forms of creative spoken word, and to allow your emotions to flow freely as they are communicated to you from the art form. Whether it be your local theatre group, the opera company, a music gig down at the pub, or a school concert, get involved and open your senses. It is good for the heart and soul, wonderful for the body and mind, and essential for us all as emotional beings as we try to communicate. Maybe even try to sing a song to your friend next time you see them! Or say a line out of a play with a bit of emotion! Communicate emotion through spoken word. It's fun! And it's essential. Thank you.

**Disability Studies Dissertation Abstracts**

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