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Writing with the 'Other': Combining Poetry and Participation to Study Leaders with Disabilities

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Abstract

In this paper, we describe the process of transformative co-authorship between researchers and a participant with disabilities. The researchers were conducting a larger study that aimed to identify different factors that shaped individuals with disabilities to assume leadership roles. Drawing from interview data obtained from the participant, one researcher wrote a poem that provided a stage for the researchers and the participant to engage in reflexive process that transformed the researchers-participant relationship to that of co-authors. This paper describes this transformative process and what everyone learned from this enriching experience.

Keywords

Leadership, Disability, Qualitative Research Methods, Arts-based Research, Participatory Research

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Writing with the “Other”: Combining Poetry and Participation to Study Leaders with Disabilities

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In this paper, we describe the process of transformative co-authorship between researchers and a participant with disabilities. The researchers were conducting a larger study that aimed to identify different factors that shaped individuals with disabilities to assume leadership roles. Drawing from interview data obtained from the participant, one researcher wrote a poem that provided a stage for the researchers and the participant to engage in reflexive process that transformed the researchers-participant relationship to that of co-authors. This paper describes this transformative process and what everyone learned from this enriching experience. Keywords: Leadership, Disability, Qualitative Research Methods, Arts-based Research, Participatory Research

Research is often conducted *on* persons with disabilities (PWD) rather than *with*. This is a phenomenon that is also common to people who may be marginalized due to other factors such as race, class, socio-economic status, ethnicity, and other minority status. There is a focus on educational and socio-emotional outcomes for PWD in published work by researchers and educators in special education. However, since researchers often do not have the disabilities that they research and write about, the extant literature could be heavily biased presenting the perspectives of the powered and the dominant groups while ignoring the voices of PWD. Thus, there is a need for a transformation in the interactional space between the researcher and PWD.

This paper describes the reflexive process of the development of co-authorship between two university researchers and a participant who is an adult with disabilities. Kitchin (2000) argues that both the perspectives of the researcher and the researched are needed, so that one may understand multiple and insider perspectives. In addition, enabling and presenting the voices of the researched and seeking their role as co-authors of the resulting text reduces power distance between the two groups; creates a sense of authenticity; and increases the credibility of the research narrative.

In this paper, we describe how the first author (henceforth referred to as *Author A*) and second author (henceforth, *Author B*) developed a partnership of co-authorship with the third author (henceforth, *Author C*) who was initially a participant in a study conducted by the first two authors.

Research Context

The benefits of workplace diversity have been documented well in the diversity literature. For example, workplace diversity has been found to contribute to organizational attractiveness (Avery, 2003; Martins & Parsons, 2007), performance (Bezrukova, Thatcher, Jehn, & Spell, 2012; Ellis, Mai, & Christian, 2013) and creativity (Pearsall, Ellis, & Evans, 2008; Shin & Zhou, 2007). A diverse workforce can also be a key for organizations to maintain a sustained competitive advantage (Roberge & van Dick, 2010). Similarly, diversity in leadership has also been linked to enhanced organizational performance (Roberson & Park, 2007).

As organizations strive to be demographically and culturally diverse, the incorporation of diversity in leadership is progressively becoming a central issue in organizations. However,

most of the research on diversity in leadership has focused only on the dimensions of gender, race and culture (Roberson, Ryan, & Ragins, 2017). Disability as a dimension of diversity has virtually received no attention in the leadership literature. This is surprising not only because there have been many notable leaders across the world with disabilities (e.g., Franklin D. Roosevelt, Ralph W. Braun; Stephen Hawking, and many more) but also because persons with disabilities (PWD) constitute the world's largest minority group (Department of Public Information, 2006). According to the United Nations convention on the rights of Persons with Disabilities, PWD “include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (United Nations, 2006, p. 4).

The exclusion of PWD from leadership studies is a major oversight in the leadership literature for at least two reasons. First, like all other minority groups, individuals with disability also deserve equal opportunities for positions of power. Second and more importantly, PWD need not be given leadership positions because of affirmative actions, but because PWD may make certain unique and valuable contributions to the role of leadership that their non-disabled counterparts may not. This is because PWDs often have to overcome many major hurdles to lead a “normal” life, and through this process may develop some unique character strengths that may help them in roles of leadership. For example, PWDs may develop high resilience as they learn to overcome their disability-related challenges, which in turn could help them become effective leaders.

To address the gap in the extant literature, Author B and Author A initiated a large study that endeavored to understand the factors that help (and hinder) PWD to emerge as leaders and be effective in their roles of leadership. The current paper is part of this large study, and focuses on the interviews with one participant who was invited to be the third co-author of this paper. The idea of co-authorship emerged when the participant’s story inspired Author A to create a research poem from this participant’s interview transcripts. After writing the poem, Author A shared it with Author B and proposed the possibility of sharing the same with the participant and inviting co-authorship in developing the poem. Sharing the poem and inviting the participant to be a co-author aimed at serving several purposes: member checking; creating a shared platform for the researchers and the researched; enabling the original voice of the participant in the narrative; and sharing insights gained through reflexive thinking by the three members of the group. In effect, this paper combines the qualitative methods of arts-based research “...defined as the systematic use of the artistic process, the actual making of artistic expressions in all of the different forms of the arts, as a primary way of understanding and examining experience by both researchers and the people that they involve in their studies” (McNiff, 2007, p. 29) and participatory research to express the voice of a PWD in leadership role. Participatory research refers to the process of involving research participants in different stages of the research in ways that are meaningful and collaborative (Cornwall & Jewkes, 1995).

Use of Poetry in Qualitative Research

The purpose of using poetry in research papers is not just ornamental, although like all forms of art it does have the capacity to enhance the beauty of things. The purpose of art is primarily to evoke emotions (Eisner, 2008). When art is included in research, the output is a product that is not just descriptive but also evocative. Poetry can be a powerful means of portraying things that cannot be adequately articulated through literal descriptions. According to Eisner, “Words, except when they are used artistically, are proxies for direct experience” (2008, p. 5). Words in poetry have the power to evoke “the provision of a set of qualities that create an empathic sense of life in those who encounter it...put another way, art is present in

research when its presence enables one to participate vicariously in a situation” (Eisner, 2008, p. 6). We used poetry in our research paper to help readers experience situations from the perspective of a PWD that figuratively allows them to walk in that person’s shoes. Or in other words, through the use poetry we attempt to bridge the gap in experiences between the participant and the reader.

The usage of arts and aesthetics in organizational research was a rare phenomenon, but such forms are gaining increased amount of attention in the field (Brearley & Darso, 2008). Denzin (2001) highlighted the need for and the importance of alternative forms of conducting qualitative research to enrich data and delve deeper into the inquiry. More researchers in recent years are exploring the use of poetry in qualitative research (e.g., Cahnmann, 2003; Chatfield, Cooper, Holden, & Macias, 2014; Edwards & Weller, 2012; Egbe, 2013; Faulkner, 2009; Furman, 2004, 2006; Naidu, 2014; Plamondon, 2014; Prendergast, 2009; Sjollemma & Hanley, 2014; Sjollemma, Hordyk, Walsh, Hanley, & Ives, 2012). Cahnmann (2003) justifies the use of poetry in research by describing how the various elements of poetry—such as rhythm, rhyme, repetition, meter, metaphor, lyricity and most importantly the spoken and unspoken messages in poetic data—enable understanding of the complexity of phenomena being examined.

Furman (2004) used autobiographical poetry to describe how he coped with his father’s illness. Speaking of the use of poetry in health research, Furman, recommended that “researchers and practitioners wanting to understand the health-seeking behaviors of those from historically oppressed communities must use methods that facilitate the expression of powerful emotions that might not always be easily expressed in a clear or linear fashion” (2006, p. 561). The first author of this paper also has a keen interest in and demonstrated the use of poetic data in research to enable voices of individuals with disabilities and their families (Cousik, 2008, 2011, 2014, 2015, 2016a, 2016b).

In the field of disability studies, poetry has been used to present the insider’s perspective that questions society’s apparent glorification of perfect bodies (Brown, 2015; Hodges, Fenge, & Cutts, 2014; Ireland & Pound, 2003; Koppers, 2009; Swain & French, 2000). Mitchell and Snyder (2001) trace the evolution of portrayals of disabilities in the arts and situate poetry’s significance and place in this movement.

Participatory Research

The use of poetry in research reports may be evocative but how can we be sure that the emotions evoked are valid? We have made an effort to convey in this paper that emotions generated through poetry are truly the emotions of the research participants. However, readers may experience similar or different emotions when they read the poem.

One of the reasons arts-based research hasn’t gained more traction in mainstream social science research is because of the perception of its questionable “objectivity, validity and generalization” (Eisner, 2006, p. 14). When it comes to validity, validity of correspondence—which simply refers to a claim corresponding with its object—is often considered the most valid form of truth (Lather, 1993). It has been noted that arts-based research methodology “runs counter to the standard foundational validity of correspondence” (Rolling, 2010, p. 109), and so arts-based researchers should rely on transgressive validities that are non-referential forms of validity which “unsettle truth regimes, implode controlling codes, and work against the constraints of authority” (Lather, 2007, p. 5164).

While there are merits in transgressive forms of validity, we take the position that doing arts-based research need not preclude researchers from aiming for validity of correspondence. This paper describes a method of validating research-poetry through the reflexive process of involving a research participant in a co-author partnership. In other words, we used a form participatory research to validate our arts-based research. Specifically, we incorporated the

practice of cooperative inquiry that emphasizes working with research participants as co-researchers (Reason, 1994).

Zajano and Edelsberg (1993) describe the development of a relationship between a researcher and a participant that resulted in both producing a co-authored text. According to the authors (p. 144), “The process of writing this tale together enabled us to address the issue of how the voice of the researched might speak alongside that of the researcher in ethnographic accounts.” At the same time, we were conscious of “the simultaneity of benefits and costs, possibilities and limits...” (Gonick & Hladki, 2005, p. 288) of such a bold venture in qualitative research.

For both voices to be expressed, heard and respected equally, it is necessary that researchers and participants engage in a fair amount of reflexivity and think about how they are affecting and being affected by the research. Pezalla, Pettigrew, and Miller-Day (2012, p. 169) argue that self-reflexivity helps “increase the transparency of... findings, and increase the legitimacy and validity of...research”. When researchers and the researched explore the research findings together and present both their individual and combined reflections, the truth claims that they make become collaborative, strong and convincing. This process serves as a member checking device (Lincoln & Guba, 1985), reduces the extent of bias in the text and more importantly, allows biases to surface, be examined and acknowledged.

In this paper, we present three perspectives drawn from interviews with one participant and a research poem that was created from the interviews. These interviews were part of a larger study that endeavored to understand factors that help (and hinder) PWD assume leadership roles and be effective in these roles. The first author wrote the research poem after two interviews with the said participant, shared it with the co-researcher and the participant and sought their co-authorship, thus eliciting “heteroglot voices” created “by the scratching of other pens” (Clifford, 1983, p. 121). We chose to tell our stories individually, in order to preserve authenticity in the narration (Zajano & Edelsberg, 1993, p. 143).

Research Participants as Co-authors

Participants of research studies are often referred to as *subjects*. This changed with the American Psychological Association’s (APA) (1994) policies that aimed to acknowledge the contribution of the people who elect to participate in our studies. While subjects—like animals—are subjected to research conditions, human beings chose to take part in research, and thus they should be called participants (APA, 1994). Making participants co-authors of research is taking this one step further, where not only is the choice of participants acknowledged but also their inputs sought in the interpretation of findings.

For example Koelsch (2013) shared her interview transcripts with her participants, and describes the combined, reflective process. Koelsch asserts that this type of member check acknowledges that both the researchers and the researched are transformed by the research process. Similarly, Smith (1994) engaged in reflexive analysis of her research where she invited one participant to be a co-author. The final text of the analysis included a section that presented the combined perspectives of the researcher and the researched. Based on Mulkay’s (1985) suggestion, Smith talks about how a researcher’s text could become “available to participants for deconstruction” and how the researcher can let go of the “interpretive privilege” (Mulkay, 1985, p. 76) by inviting participants to co-author the text, and strengthening one’s own interpretive claims about the researched. Finally, Huber, Caine, Huber, and Steeves (2013) describe the creation of counter narratives or “counter stories” in their research with teachers and children.

The Study

The goal of this endeavor was to invite the perspective of the participant on the poetic representation of her story, check the accuracy of representations and meanings about her story creatively expressed in the poem and finally merge the voices to create a harmonic presentation of the transformational process of co-authorship. Author A wrote the poem after the second interview with the participant, shared it with Author B and the participant, and invited their critique and co-authorship. The poem was created by selecting key themes in the interview transcript and includes a few direct quotes. The participant and the co-researcher read the poem and provided their reflections. The participant verified the accuracy of representations in the poem and reflected on its construction and researcher's interpretation. Finally, she provided suggestions to re-word parts of the poem, which was welcomed by the author of the poem and it was rewritten accordingly.

We have organized the following section in this way:

- 1) Researcher participant phase: Here we introduce ourselves in our own voices.
- 2) Poetic re-presentation of interview data and first author's reflection: We present the poem as it was first written by Author A, and the reflections of Author A.
- 3) Second author's reflection on the poem: We present the reflections of Author B
- 4) Revised sections of the poem: We present the role shift of participant to coauthor phase and verses which include her comments.
- 5) Reflection about role shift-participant as coauthor: We present the participant's reflection on the process of her role change and on the poem itself.

Who We Are

The following section provides a glimpse into who the three authors of this paper are, in our own words. Each of our lives are deeply connected with disability, and we have tried to weave the individual strands together. Each author had the right to include as much background information about themselves as they wanted, and this section has not been edited for length, to preserve the authenticity of their stories. The authors also had the freedom to use whatever terminology they deemed fit to refer to people with disabilities.

Author A

I am a faculty member of special education in a university in the Midwestern United States. I had worked as a special education teacher for nearly two decades in India providing educational support for people with a variety of developmental disabilities, across the full life-span. I constantly sought positive portrayals of people with disabilities and urged my students at the university where I worked to question the deficit model (Harry & Klingner, 2007) employed in special education. In the deficit model, children are perceived to have inherent deficits and hence acquire disability labels. The deficit model, based on the medical model of disability as a fixed identity is promoted by regulations such as the Individuals with Disabilities Education Act (IDEA) but people with disabilities may have a sense of self that does not put their disability in the foreground (Watson, 2002).

I constantly strived to teach my students how to recognize strengths and leadership qualities in every child, regardless of the label and promote these qualities through a curriculum enriched by this understanding. Hitherto, I have been researching about children with disabilities, and conveying/expressing their ideas through my lens-an empathetic one as I thought. Deep inside, I was dissatisfied because even though I had the institution's IRB approval to represent children's voices, it was still just that-a re-presentation. It was not their stories told by them, but my interpretation of their stories with carefully chosen quotes from my participants to support my claims. Like most people, I had power at two levels-first as a non-disabled person without having to face society's ableistic constraints and second as a faculty member of a university wearing the "privileged cloak" that officially permitted me to research about others (Cousik, 2015).

Thus, I was very happy when I realized that the poem provided an opportunity to loosen some of those constraints that researchers experience and invite a participant to co-author the paper. I was quite conscious of possible rejection of the offer and prepared to have my creative work critiqued, questioned, edited and appreciated. I realized I was treading on a scarcely explored territory in the area of research with people with disabilities and was excited and looked forward to gaining many insights from the process.

Author B

I teach organizational behavior and leadership at a midsize university in the Midwest region of USA. My research interests are diverse and continue to evolve. But if there is one thread that runs through all my research, it is my interest in trying to understand the nature of different obstacles faced by individuals and the various mechanisms through which they overcome those obstacles to be happy and effective in their lives.

I started working on leaders with disabilities a couple of years ago by collaborating with the first author of this paper. My motivation to study leaders with disabilities was partly opportunistic, because in my academic searches I did not find a single peer-reviewed study on leaders with disability. This seemed like a major oversight in the field of leadership, because history is filled with numerous notable leaders who had one or more form of disability.

There was also a personal reason I became interested in studying people with disabilities. I am the younger sibling of a person with intellectual disability. While growing up with my disabled brother, I wanted to take up a profession that would allow me to work for the betterment of disabled individuals like my brother. So, after completing high school I joined a professional undergraduate program in India that trained students in special education and behavior modification. On graduating from the program, I also worked with children with disabilities for two years. Later, as I was advancing my education in the field of psychology, I got a job opportunity to join a large corporation as an officer trainee. That was the beginning of my career in the corporate sector, and I gradually drifted away from the field of special education. Eventually I got a Ph.D. in Business (Organizational Behavior) from a major university in USA, and ended up as a faculty in the same field. I thoroughly enjoy my research and teaching in the field of organizational behavior, but periodically I have felt a little guilty for moving away from my original goal of making a difference in the lives of people with disabilities.

I wondered if I could still do some work in the area of disability, but I did not see any way to connect my research in the field of organizational behavior with disability. Despite having been educated and trained in both the disciplines, I could not see any interesting connections between the fields. It was as if like, the two fields existed as separate compartments within my head.

Eventually though I did get the insight to start studying leaders with disability. As I reflected on the life of my brother, I realized that even he was a leader in many ways. In the field of Organizational Behavior, we typically view leadership as a goal-directed process of social influence. Although people with intellectual disability are never seen as leaders—even by the professionals working in that field—I could not ignore the tremendous influence my disabled brother has had in our immediate family, extended family, and even in the neighborhoods he has lived in. Psychologists and special educators who work with children and adults with intellectual disabilities often view the influencing process of these children as problematic behaviors that need to be managed. There is certainly no denial of existence of manipulative problem behaviors in some children with intellectual disabilities—even my brother had many—but growing up with my brother I had also noticed innumerable instances of influence where his altruistic and equitable nature came to the fore. I thought to myself, “If my intellectually disabled brother has social strengths that has helped him behave in leader-like fashions, then sky’s the limit for people with other disabilities.” That’s when I joined hands with the first author of this paper, to explore the character strengths of people with disabilities who were in some formal leadership roles.

Author C

I was recruited to participate initially as a research subject by Author A; she contacted me via e-mail and asked if I would consider participating in her study with Author B. They informed me they wanted to examine the roles that people with disabilities had in leadership, whether professionally or in a social context. I eagerly agreed as I see any opportunity for educating others about disability as a worthwhile endeavor. I am a Caucasian female living in the Midwest, and I have a Master’s degree in speech-language pathology. After returning from graduate school, I underwent a surgical procedure that was meant to correct my spinal cord injury but ended up exacerbating it. For that reason, I was unable to pursue my original career goal as a speech-language pathologist; instead, I accepted a position as a part-time lecturer at the same university as the other two authors.

I am now working in the same department in which I earned my undergraduate degree. I have been teaching for two years and I believe I am in a unique position as an individual working at the collegiate level while living with two disabilities.

My primary disability is a form of dwarfism, called spondyloepiphyseal dysplasia, which causes short stature. I stand just over three feet tall and use a motorized wheelchair for mobility. One of the secondary characteristics is a malformation of the cervical vertebra which led to my second disability, a spinal cord injury. Though either of these conditions can present challenges of their own, combining them has given me a unique set of circumstances and limitations; therefore, I have a unique perspective on life. I wanted to bring that unique perspective into the research study, and throughout the interviews I repeatedly drew distinctions between the two disabilities.

First Version of the Poem by Author A

I was inspired to write the poem after I met Author C. Her story had a deep impact on me: she did not foreground her disability as her primary identity; and her story unfolded chronologically with significant twists at crucial phases of her life that seemed to have made her who she was today. In my vivid imagination, I began to write her story from her perspective, visualizing from an able-bodied (and hence from a societal point of view- privileged) perspective-how it must have felt growing up with challenges within and without. Here is the first version of the poem:

Open the door

Open the door!
The knob sat impassive
Impervious to the hot
Molten lava of pain
That tore up from the
Base of my spine
Enscenced on a comfy cozy
Cushion on black rubber wheels
To the tips of my trembling
Hands that knew they could
Never reach it let alone grasp.

Open the door!
The kids laughed innocent
Ignorant of the humiliation
That coursed through
My veins
And clasped my tender heart
Which nested in my
Torso shorter than short
Pounding deafening till
My brain told me they would
Never get it nor want to

Open the door!
Mom refused knowing
Instinctively how to
Fuel my growth
You shall depend
On no one but self
Nurturing pushing
Me forward till all in me expanded
The intellectual the emotional
The perceptual and the spiritual
All except the soon to be cadaver

Open the door!
The pastor heard enlightened
A latch soon turned into a switch
So I could enter, pray, lead
Seek my own path
Roughhewn forever undulating
Dispose of evanescent quagmire
Persist practice patience
Transgress pain suffering
Resolute disavowing inertia
The key to the doors lie within

Reflection on the Poem by Author A

After both the interviews were transcribed I read the transcriptions thoroughly and selected crucial events in her life and listed them in a chronological order. During each phase of her growing up, I noted down events, situations and settings (including the physical world) that seemed to signify her own views and societal views of her disability and how it affected her daily life. Rather than what she said, what she did not say seemed to strike me with more intensity. For example, although she talked about how her peers' attitude towards her was initially, she completely desisted from blaming them for being negative. In another instance, when she talked about falling from her wheelchair on the pavement, she refrained from discussing the pain and discomfort that that must have caused her. And finally, when she talked about the church door being inaccessible, she discussed how it was an opportunity to change the world (by educating the pastor and other church members about accessible buildings) rather than accusing the church of being ADA non-compliant.

As I began to write the poem, I decided to use the first-person voice "I" which helped me connect with her story very personally, feel what she may have felt, and experience the myriad emotions that may have coursed through her mind, rather than the second person voice "She" which would have likely presented a detached perspective of the "other". I was amazed at her calm acceptance of these challenges. Had I been in her shoes, would I have had her strength and tenacity? Would I have the courage to independently overcome society's hurdles and grow intellectually and spiritually as she had? Her narration had no direct negative attribution to any event in her life. Instead, only a matter of fact tone, as if at each hurdle, she literally picked herself up, dusted her hands and moved on.

Her story provided me several valuable insights that I could draw from in my work in the area of inclusive education. First, it reaffirmed my belief in the necessity and importance of training and educating students in K-12 settings about diversity and human variability, promote acceptance and prevent bullying. Second, it served as an excellent example of her belief in individual courage and self-development, qualities that made her a successful climber of the academic ladder. These are qualities that every future educator must look for in students with disabilities in K-12 settings. The notion of presumed competence that these indicate, are likely to prevent teachers from embracing the highly prevalent, deficit model of disability, which adversely affects the quality of education these students receive.

Reflection on the Poem by Author B

Reading the above poem reminded me of a famous quote by Carl Rogers (1989) who had said, "What is most personal is most general" (p. 26). The poem describes the personal challenges of a person with disability and how she overcame those challenges, eventually succeeding in being a catalyst of positive change in her community. The struggles and accomplishments described in the poem were of the third author, yet they resonated deeply with me.

While reading the poem, I felt like Author A had intuitively captured the journey of a leader with disability really well, with each stanza illustrating a major stage in this journey. The first stanza talked about the *personal challenges* of a person with disability. People with disabilities have to fight many battles throughout their lifetime, but their first battle starts with overcoming the overwhelming challenges arising out of their disability. In case of a person with dwarfism, the challenge may be as simple as being able to reach the door knob and open the door independently. The task of turning a knob to open a door is so simple that we often take it for granted, but for a person with disability this simple task could be extremely difficult.

Such challenges often limit what people with disability can do and accomplish in this world and the workplace. This sometimes makes them the objects of ridicule. This is a *social challenge* that people with disability have to overcome. As if their physical impairment was not enough, society's attitude towards them creates a psycho-social challenge that they also have to overcome. This is the focus of Stanza 2.

Howsoever big the challenges, PWD gradually learn to overcome the limitations arising out of their impairments. This is a *personal victory* for the PWD and is the focus of Stanza 3. As so beautifully illustrated in the poem, the process of overcoming some of the limitations imposed by one's disability doesn't happen easily. It often happens with the support of caring individuals. However, care here doesn't automatically mean doing things for the person with disability. Instead, it is often achieved by a supportive pushing of the PWD to do be independent in life.

With that personal victory of being able to do certain things on one's own finally comes the confidence and courage to take up bigger challenges that of making a positive difference in the lives of people other than the self. When a PWD strives to bring about changes that are beyond the immediate personal self-interest, s/he essentially becomes a leader, whether or not s/he has a formal leadership position. Since leadership is described as a social-influence process, the transformation of a PWD to a leader would be considered a *social victory*, which is the focus of Stanza 4.

Thus, in many ways people with disability may grow up to be mentally tougher individuals than people without disability. The German philosopher, Friedrich Nietzsche (1888/2007) had once said, "What doesn't kill him makes him stronger" (p. 175). This is not always the case. For example, sometimes exposure to extreme or prolonged stress weakens us and makes us susceptible to serious illnesses and hardships. However, as noted by Nietzsche, people who do successfully overcome their personal challenges do come out stronger. Seen from this perspective, PWD go through a trial by fire, and the ones who do succeed in clearing these trials may come out stronger with higher than average potential to be leaders of change.

Revision of Poem by Author C

Following two hour-long interviews with Author A and Author B, I was sent a write-up of a poem that Author A crafted using the interview material. She invited me back into her office to discuss the write-up and asked me to take a larger role in the research project. It was at this point that she invited me to be a co-author alongside her and Author B. We have reviewed the poem numerous times since then, collectively and individually, and the entire project has evolved significantly since the initial proposal was made to me.

Here are the selected lines from the poem where my comments are inserted in italics:

Lines from Stanza 1

...To the tips of my trembling
Hands that knew they could
Never reach it let alone grasp. [*This is one of the hardest parts of having a spinal cord injury – knowing that my brain can communicate that "message" to my hand, finger, etc., but my body may not respond in the way I want it to.*]

Lines from Stanza 3

...Mom refused knowing...
[*The growing up I had was so subtle that I didn't know how my parents' actions (or*

inactions) were preparing me to live life in an “unadapted” world. This aspect may also make it more difficult for me to accept help in other areas.]

Lines from Stanza 4

...The pastor heard enlightened
A latch soon turned into a switch [*Having the experience of taking this problem to my pastor and church leadership team and having them listen was so empowering. It was the first time I truly realized I could affect change for myself and others, and it has become a goal of mine to continue using my experiences to help others.]*

...Dispose of evanescent quagmire...
[*This sentence was changed to “Dispose the fleeting danger of the quicksand of negativity”. I asked the first author to change the original words in this line and replace complex sounding words with everyday language. I felt that my feelings were better expressed this way.]*

Here we present both the versions of the last verse of the poem, with changes by Author C in italics:

Roughhewn forever undulating
Dispose of evanescent quagmire
Persist practice patience
Transgress pain suffering
Resolute disavowing inertia
The key to the doors lie within

*Rocky terrain forever
Dispose the fleeting quicksand of negativity
Persist, practice, patience
Transgress pain suffering
Resolute disavowing inertia
The key to the doors lie within.*

Reflection by Author C on Role Shift from Participant to Co-Author

When I agreed to participate in this research project, I expected to go through a couple interviews, perhaps provide some feedback for the final article, and in general, have a relatively “low profile” in the project. I didn’t know what to expect exactly, as all of my experience with research has been in the quantitative form - collecting and analyzing numerical data - and I had never thought of qualitative research. Through one of my classes in my graduate program in speech-language pathology I learned how to perform an ethnographic interview, so I recognized some of the characteristics during my own interview, and I appreciated having the freedom to expand on my thoughts throughout the entire process.

I appreciated the fact that putting together the poem took more than one day, or even one week or one month; it has taken a lot of thought and collaboration between the three of us authors, and everyone’s opinion has been valued and respected equally. I think that is a key component in having the poem carry “weight” in a research article.

In preparing to write out my thoughts for this paper, I have reviewed both the original and revised versions of the poem. I find myself wondering what notes Author A used for writing - which statements that I made stood out to her as important? If I were to listen to the recordings, would I highlight the same parts? Given that it’s my life and experiences, I’m

guessing different parts would stand out more, and I find that intriguing. Whether we realize it or not, our own lives and experiences color our perspectives; we each have opinions and biases that influence how we view the world around us. Despite trying hard not to rely on those opinions to make decisions or judgments, it is inevitable. I think going through this exercise, this self-examination, has showed me a clearer picture of how everyone has those idiosyncrasies in their belief systems, no matter who they are or what life experiences they've had.

My favorite line from the poem is one that came from the revised version: "Dispose the fleeting danger of the quicksand of negativity." The reason that is my favorite line is because I view it as a personal reminder; it can be easy to get sucked into the negativity that comes with the daily challenges, but when I allow myself to be drawn into it, I forget about all of the positive things that have come about since my SCI (spinal cord injury): I have found a way to participate in a career field I love through teaching the future professionals, I have discovered a desire to advocate for individuals with disabilities, and I have learned even more about the disparity between people involved in faith communities and people with disabilities involved in faith communities. In each of these areas, I find myself drawn to improve, either myself or the situation as a whole. Some of these things have already been acted upon, others will take diligent planning before changes can be made.

Concluding Thoughts: What Did We Learn?

There is a great need to give PWDs who participate in research, a voice in the research process. Currently most research papers on PWDs restrict this voice to only inserting carefully selected quotes from interviews into the text of the paper. However, this does minimize researcher's bias slightly but not to a significant degree, because PWDs rarely get a chance to provide their interpretation on their quotes.

Co-construction of the text enabled us to see one another's viewpoint more clearly. Our positionalities provided multiple meanings and value attributions to the knowledge created. However, when the final draft of the paper was shared with Author C, the researchers' candid perceptions in the poem and reflections posed a sense of hope but also many risks. Like Gonick and Hladki (2005) we were highly conscious of how such a "production of knowledge coils and frays in predicament and excitement" (p. 288). After she read them, it was possible that the participant could she change her mind about co-authorship. She could also disagree with many ideas expressed or she could find some statements inappropriate, leading to conflict and mutual discomfort. She also had the right to ask that her story not be published. Thankfully, our story followed a positive path, with hope for the relationship to be sustained beyond this adventure. The risk paid off. As Author C expresses in her reflection post-poem, the researchers' viewpoints had elements of surprise, shared meanings, shared ideas and confirmation for her. Rather than posing possible risks of discomfort, confusion and denial that such an open and honest sharing of the researchers' perspective with the researched may have produced (Zajano & Edelsberg, 1993) it actually strengthened the findings/interpretations. Like Zajano and Edelsberg (1993) found in their study, "In the process of making the tale accessible to the readers" our text "is understood anew by the writers, and thus embellished, shaded, nuanced, and changed" (p. 156).

From the researchers' perspective, the poem served to crystallize the researchers' impressions about the participant and her story and provided a vehicle for expressing the same. The co authorship helped explore, validate and strengthen common meanings that emerged from the poem and also served as a member-checking device. Thus, it helped explore and reduce inherent biases that the researchers' perspectives may have produced.

In turn it provided the participant an insider's view of the research writing process, and qualitative research in particular. It opened up a window to the mind of the researchers—the impressions that they gleaned about the participant from the interviews, by writing the poem and by finally sharing, rewriting and reflecting on the process. The co-authorship also revealed how both groups were able to empathize with each other, think harmoniously on the issue of disability and factors that shaped leaders.

In the end, each author had something to take away from this process—the first and second author gained deep insights about the ups and downs of growing up in a disabling society and an inspiring story that informed the body of knowledge in the areas of leadership and education. The participant reaffirmed her own faith and beliefs in her strengths, support systems and attitudes and through this reflexive process of co-authorship, valued the opportunity to communicate to the world the qualities that shaped a leader with a disability. Finally, we recognize that this intentional process of engaging in this type of transformative researcher-researched relationship has considerably shifted our positionality, our roles and the power dynamics between the two groups. The participant was no longer the “other” to the researchers but a co-author with equal status in the creation of this text and held promise for a continued and sustained relationship.

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