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Disabilities Disabilities: A "Two-Way Mirror"

Abstract

There is nothing more intriguing than well-reported documented stories of real life experiences and genuine autoethnographic dialogue. When writers communicate and relate stories about the self and their experiences and include others who share a personal story, there is an amazing connection, unique intensive and extensive understanding and interpretation, and a cultural and social exchange in an autoethnographic representation of self and the respective culture of study. A dialogue generated among the authors as educators as they shared stories inside and outside the disabilities culture was the performance and autoethnographic delivery in Phil Smith's book, *Both Sides of the Table: Autoethnographics of Educators Learning and Teaching Within/in [Dis]ability*. For Smith's purpose, both sides of the table represent both parties negotiating an academic Individualized Education Plan (IEP) for individuals with disabilities. The transitions from self to group and the ability to move freely inside and outside the culture as a member of the culture, presents a "wider lens" as one often hears in the autoethnographic and ethnographic language needed to gain a more complete picture of what it is you want to know and learn, and what is permissible to reveal. An autographic lens is widely accepted for this dialogue (Chang, Ngunjiri, & Hernandez, 2013; Creswell, 2013; Ellis, Adams, & Bochner, 2011). Pragmatically, autoethnography was a method realistically supported by the voice of these educators with a unique understanding of their own disabilities world and a story to tell.

Keywords

Autoethnography, Disabilities Education, Dialogic/Performance Analysis

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Disabilities Disabilities: A “Two-Way Mirror”

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*There is nothing more intriguing than well-reported documented stories of real life experiences and genuine autoethnographic dialogue. When writers communicate and relate stories about the self and their experiences and include others who share a personal story, there is an amazing connection, unique intensive and extensive understanding and interpretation, and a cultural and social exchange in an authoethnographic representation of self and the respective culture of study. A dialogue generated among the authors as educators as they shared stories inside and outside the disabilities culture was the performance and autoethnographic delivery in Phil Smith's book, *Both Sides of the Table: Autoethnographics of Educators Learning and Teaching Within/in [Dis]ability*. For Smith's purpose, both sides of the table represent both parties negotiating an academic Individualized Education Plan (IEP) for individuals with disabilities. The transitions from self to group and the ability to move freely inside and outside the culture as a member of the culture, presents a “wider lens” as one often hears in the autoethnographic and ethnographic language needed to gain a more complete picture of what it is you want to know and learn, and what is permissible to reveal. An autographic lens is widely accepted for this dialogue (Chang, Ngunijiri, & Hernandez, 2013; Creswell, 2013; Ellis, Adams, & Bochner, 2011). Pragmatically, autoethnography was a method realistically supported by the voice of these educators with a unique understanding of their own disabilities world and a story to tell. Keywords: Autoethnography, Disabilities Education, Dialogic/Performance Analysis*

Sharing Personal Stories: An Autoethnographic Memoire Moment

As an educator, I have spent my early academic career working with children and adolescents and currently in higher education. I have witnessed students with diverse abilities, disabilities, and exceptionalities since the early 70s and 80s while teaching in developmental classrooms, residential treatment centers, private and public education settings, and juvenile detention/ lockup. As one imagines, the challenges were monumental. The inability for one youth, for example, to master his native language and then expected to master the English language was an epic challenge. This juxtaposition of two languages presented numerous issues, and whether there was a hidden disability or the inability to operate in or master both languages simultaneously, the problem, unfortunately, manifested in behavioral issues and actions for this adolescent and a trajectory into the juvenile justice system.

Similarly, Smith (2013) speaks to the injustices in the education system embedded within the authors' stories. Granger's story, *Who knew School Could be so Cruel*, resonates: “I didn't realize that we had to copy the words letter for letter, exactly as they appeared in the word-bank. If I had known that, things would have been different” (p. 37). Similarly, Grace's *Autistethnography* memoir further speaks to the injustices in the disabilities classroom: “I found they had coated the windows with something that made the view of the outside all

browened and distorted and wrong” (p. 94). Discernably, the negative experiences of self in and outside an education classroom left long-lasting imprints.

Smith (2013) has done an exceptional job of sharing the stories and experiences reported from the lives of renowned educators with noted disabilities or related disabilities or from a respective family member with a disability. Smith embedded his own work and each chapter became an autobiographic platform for projecting his/her own voice and narrative in a poignant story and shared experience. As a culminating event, Smith interviewed the authors in a symposium-style approach and dialogic exchange, and provided a forum to collaboratively share experiences from the experience of writing the story. For Smith, his poetic analysis and contribution revealed how he intended to organize the internal and external analysis of the stories from the “essence of the experiences” (Creswell, 2013, p. 80), and the empathy raised when hearing other authors’ personal struggle. Additionally, Smith’s daughter played a unique role in conversation with dad on the “porch” and together, contemplated the complexity of disabilities in a unique dialogic display of “questions, theories, and subjectivities” (Smith, 2013, p. 5). The conversation reflected the importance and power of the disabilities research and what is missing from the literature:

Research about disability can be—maybe should be—done by, or at least in partnership with, people with disabilities. It doesn’t need to be done by white, middle-class, heterosexual, male professors in button-down shirts and tweed jackets who work at universities—dead white men, I call ‘em. It doesn’t need to be done in five-chapter dissertation formats—introduction, literature review, method, results, discussion....Instead, disability studies scholarship and research representation is going to look more like--*needs* to look more like—stories and songs and poems. (Smith, 2013, p. 272)

Moreover, Smith’s poetic delivery in his chapter titled, *This Closet*, reinforced his own internal strife, perception, and inward voice, possibly depicted by what Denzin (2011) refers to as a “multilayered pedagogical and literary performance ethnography” (as cited in Smith, 2013, p. 8; Denzin, 2003), imaged in a symbolic, two-way mirror-- a reflection from past experiences and “living with a disability” (Smith, 2013, sec. 2).

The Phenomenon

Smith (2013) was purposively drawing attention to the collective, shared, and common experiences of the authors and phenomenologically by reaching the *essence of the experience* with a political and academic twist. Creswell (2013) provides a similar sentiment: “It would be important to understand these common experiences in order to develop practices or policies, or to develop a deeper understanding about the features of the phenomenon” (pp. 80-81).

Respectfully, this book review authenticates the researcher’s exchange of information, conversation, and dual dialogue in order to understand the phenomenon and support academic acceptance. Many individuals have suffered with the stigma and a myopic portrayal of unwarranted labels, including the educators in Smith’s book. The experiences presented as remarkable, insightful, and evocative stories filled with disbelief, sadness, joy, acceptance, or rejection. Smith’s purpose was surely to provide that additional insight into an exploratory approach and journey of the self within the culture(s), and an in depth understanding and acceptance of the phenomenon.

Powerful Messages/Shared Experiences

Smith (2013) would no doubt support and reinforce the importance of taking risks. The disabilities podium is peak for raising consciousness and acknowledging an analytical depiction of the real issue(s), and for the educators to gain a sense of actualization without the predesigned stigma and disabled identity label. How to survive in the disabilities climate resounded in Smith's book. Clearly, it was important for all the players to "cultivate resiliency" (Coutu, 2002, p. 2) in order to manage the lived experiences. "Confronted with life's hardships, some people snap, and others snap back" (Coutu, 2002, p. 2). Smith's message may be subtle, but conveyed with some urgency for educators to share an understanding, interpretation, and meaning of the experiences. The authors were willing to explain their purpose and need for writing the anthology, and the necessity of sharing the experiences in order to gain the deserved attention from years of underrepresentation and misrepresentation. For the educators, it was important to establish a true sense of self and belonging and that meant taking risks.

Interpretations

This is a subjective moment for introspection, observation, and collection. The educators' experiences emanated from acknowledging their disabilities (or family member(s), and authentically sharing the interpretations and meanings. Self-reported experiences will stir controversy in the research arena, but knowing what we know becomes the impetus for creating authentic stories, poems, and other vividly imaged experiences of each self (Ellis, Adams, & Bochner, 2011). The analysis of the self inside and outside and within the culture of study makes for a prodigious transition. How others see you inside and outside the culture is a powerful "subjective voice" (Smith, 2013, p. 18). The pathway for the authors is paved with a robust voice and multilayered performances:

Erin: Why not invite everyone to the table? I wish everyone would be involved, and write about disability, because then we would have dialogue. Right now, there seems to be very little of what is going on. We need more, more, more. (Erin in Smith, 2013, p. 256)

"Autoethnography has truth. Autoethnography opens up a space of safety in which others can share" (Smith, 2013, p. 254):

The people who went there were real people, without real families, stories, and lives. They were not "crazy" or "handicapped" or abnormal. They were folks like my grandmother, looking for help and support. (Harold in Smith, 2013, p. 155)

Some people with autism are said to not recognize when they are in dangerous situations. Do we in our family have autism because we have put ourselves in dangerous situations like this? Is what happened to David a result of having autism or being an Albee? (Albee in Smith, 2013, p. 240)

Experientially and materially, this is some of the most authentic writing I've ever done, and if the point of research is to better understand the world, and to engage in building a collective or shared understanding of the complexities of

the world, then this work certainly “counts” as research as far as I’m concerned. (Smith, 2013, p. 252)

In Kotel’s story (Smith, 2013, p. 199), the author speaks of being blindsided when her daughter was born with Down syndrome. She talks about how everyone shunned the birth of her daughter and her as a mother:

Once she entered the world, I waited for someone to say something like, “Congratulations” or “It’s a girl.” But no one did. I remember the sudden silence the moment she was born and was held in the hands of the doctor. No one said anything. I waited some more. Still silence. (p. 204)

And for the Albee family, being an Albee, the author tells, is a vivid story portrayed with a cast of individuals who all displayed varying traits and characteristics, yet all were accepted in and outside the culture:

Having a brother who has the label of autism has made me more than just an advocate for people with disabilities. It has made an activist. I say exactly what is on my mind. (Albee in Smith, 2013, p. 243)

Summary

As the stories unfold, the reader has the ability to take on a unique panoramic view to gain an understanding and interpretation beyond what had been the initial scrutinizer –the social and psychological profile of an individual with a disability. Smith provided that closing forum specifically for all the educators to share their experiences “in order to inform, expand, and transcend this text” (Smith, 2013, p. 247), and a “look to the future” (p. 263). He accomplished his mission in hopes of stressing the need for a true paradigm shift in disabilities education and the need to stop segregating, labeling, and stigmatizing individuals with disabilities. “It forces people to be separated from others, it creates segregation, it creates oppression that people with disability experience” (p. 265). Perhaps the stories shared is the way to begin to understand how to build the “bigger, more important, more radical and revolutionary project” (p. 276), and to support the power of voice and personal lived experiences. Educators are encouraged to revisit disabilities education and dialogue together in a reserved seat at *both sides of the table*.

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