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disability and leadership.

EXCEPTIONAL LEADERSHIP

Introduction

There have been many notable leaders in history who had one or more forms of disability. However, systematic studies on leadership among people with disabilities (PWDs) are practically non-existent, both in the leadership and disability literature. To bridge this gap, we conducted a qualitative study that focused on understanding the factors that help PWDs reach leadership positions and be effective in their leadership roles.

Research Questions

A thorough literature review revealed a paucity of research in the area. We found one book (viz., Wilkinson, 2009) that described nine cases of PWDs in leadership positions, a couple of research articles (viz., Emira et al., 2018; Luria et al., 2014), and a few others that discussed it from a disability justice perspective. To better our understanding of PWDs in leadership positions, we formulated the following broad research questions:

1. What personal and contextual factors help PWDs attain leadership positions and be effective in their leadership roles?
2. What obstacles do PWDs face in leadership careers, and what strategies do they employ to overcome these obstacles?

Methodology

Upon approval by the Institutional Review Board, Purdue University, we employed a snowballing technique (Birnacki & Waldorf, 1981) to recruit participants for our study. We interviewed 29 PWDs in leadership positions (17 from India and 12 from the US).

Participants'

diagnosis included ASD, VI, HI and PI. We got over 70 hours of interviews that we analyzed using a grounded theory approach (Strauss & Corbin, 1994). We identified patterns in their responses to develop a fresh theory of leadership emergence and effectiveness among PWDs.

Key Findings

Four broad characteristics of leaders with disability have emerged from our analysis.

1. **Personal Responsibility:** Participants in our study did not expect any charity from their employers, the government, or the society. They placed greater emphasis on taking personal responsibility of their condition and taking the necessary initiatives to change the status quo.

2. Strong Will & Persistence: Participants in our study had to overcome numerous personal and organizational obstacles over long periods of time to achieve positions of leadership.

We are unsure how much of the hardiness of our participants was inborn traits and how much it developed in response to those obstacles, but it was a distinct strength in them and helped them be effective in their leadership roles.

3. Humility & Gratitude: An interesting paradox about our participants was that they were also very humble. While they took pride in their achievements, they were also mindful and grateful of the all the help that they had received along their career path.

4. Compassion: Perhaps because of their heightened sense of gratitude, leaders in our study were compassionate to the needs of others. Many leaders in our sample actively worked towards bettering the lives of people who had disabilities similar to them.

In addition, participants especially from India, were deeply involved in faith and spirituality, and they derived their strength from their spiritual practices. Overall, we found support for our argument that PWDs deserve opportunities for leadership not just because of their rights as human beings (Nussbaum, 2006; Silvers et al., 1998) but also because they may have character strengths that have been found to be associated with effective leadership.

Insights from our study have been presented at three international conferences (such as the EQRC, CEC, and OBTC) and published in two international journals (Cousik et al., 2017; Mishra & Cousik, 2021) . Two other papers are under works for submission to journals.

Implications for Individuals with ASD

As the focus of this compendium is on individuals with Developmental Disabilities, we restrict our discussion on implications for individuals with Autism Spectrum Disorders (ASD). In our study, three of our participants had been diagnosed with ASD. In addition, we also asked all our participants to provide suggestions for teachers to promote leadership skills in children.

When Deficits become Strengths

According to DSM 5, characteristics typically associated with individuals with ASD include social skill issues, lack of empathy, hyperattention to select stimuli, and adherence to structure (American Psychiatric Association, 2013) . These characteristics, though commonly perceived as deficits, can actually be used to their advantage and facilitate their roles as leaders.

For example, all our participants with ASD believed in cutting to the chase or focusing on the task at hand to the exclusion of all else, when they were asked to lead group projects. In one participant, Tracy's words "... anytime there were groups projects or anything like that I always ended up taking a leadership role because—excuse my language—I just wanted to cut through the bull***. She also said that people "weren't getting things done because they were busy socializing, but I did not want to be part of any of the socialization" and accomplished more. Ben shared that he could work up to nine hours continuously on an assignment, because of his ability to hyper-focus on a single task. Chris, the other participant also stated that he actually saw his lack of need to socialize as an "upside" and said "I'm not as concerned of what other people think of me... which is incredibly powerful."

The negative effects of peer pressure and peer conformity are well-studied (Santor et al., 2000) , and thus this typical characteristic of ASD can actually serve as a protective factor, and can facilitate the career path of individuals with ASD.

Additionally, their adherence to routine and structure helped them immensely in being efficient at their jobs. For example, Tracy said “I need to be organized and have structure and pattern in my life and setting those up and making plans. I am a list maker and...I love deadlines because it gives me a goal that’s time sensitive.” The high emphasis on orderliness can be viewed as a sign of high conscientiousness, one of the big-five personality traits that “is one of the most reliable predictors of work outcomes, including job performance, leadership, income, and occupational attainment” (Roberts et al., 2014, p. 1) . Learning from Risk and Failure Parents and teachers are generally protective of children with disabilities and take great measures to protect them from taking risks that might lead them to failure. According to Niehues, risk is, “...now most often perceived as danger or threat...” (Niehues et al., 2015, p. 1) .

She argues that when parents allow their children to take risks, children learn practical skills critical to their daily lives. Similarly, our participants recommended that teachers and parents allow children to take risks, fail and learn from their failure. For example, Chris said that failure lead him to explore his own path to leadership and said “...it took a lot of failed paths to get there, so it’s not, like I just went, “Oh, I’m gonna do this. It’s like, I’m gonna do this twice, but I’m gonna fail, and then find, you know...” Tracy concurred with this and said “I think if they want to be a leader they need opportunities. Opportunities to be a leader but also opportunities to make mistakes because that’s how they learn...I saw this meme where success goes on one branch and failure goes on another branch but that’s not how I see it. Success and failure are on the same branch and eventually you will reach success through those.” Additionally, she questioned the grading system in schools and said “I don’t like the whole grading system because it makes it seem like failure is bad, whereas what you really grading is their effort”.

Advocacy and Compassion

Finally, like the majority of our participants, those with ASD also were staunch advocates of people with autism and disabilities in general. For example, Chris held events at his workplace as the head of his unit, to mentor and promote talents of youth with autism. Tracy was a part of different advocacy groups on social media and planned to start a leadership development camp for individuals with disabilities, where leaders with disabilities could serve as mentors. Finally, Ben had started an advocacy and support group for young adults with autism at his college.

Conclusion

The leaders in our study were exceptional on several dimensions. While exceptionality is usually seen as negative in the disability literature, these participants showed that the same exceptionalities can become character strengths and valued personality traits. When the exceptionalities are appropriately framed and nurtured by family and professionals working in the field of disability, they can enable PWDs to have highly successful careers.