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Media Review: Disability, Not Invisibility: My Experience with Chronic Illness (2019)

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Joyce: Disability, Not Invisibility

TEDxTalks (2019, July 1). Disability, not invisibility: My experience with chronic illness [Video]. YouTube.

https://www.youtube.com/watch?v=tGYU8T8upzU

The TEDx Talk, *Disability, Not Invisibility: My Experience with Chronic Illness*, features sophomore Florida State University honors neuroscience student, Victoria "Vicky" Potter's experiences with disability, including the grief and gratitude she feels. She speaks to the stigma associated with disability and makes a call for allyship that has great potential to influence students of various backgrounds and experience levels. Just short of 14 minutes, the video could be shown at the beginning of class and discussed later in the same class period. Alternatively, because the video is free and publicly available on YouTube, alongside accurate captions, instructors may find it appropriate to assign for home viewing.

The video begins with a jarring push that requires viewers to examine their own personal biases. Potter, seated in a wheelchair upon a stage, asks the audience in front of her, "How many of you think I need this chair?" Many in the audience raise their hands. Potter stands and asks, "How about now?", prompting several to lower their hands. With this simple but eloquent demonstration, Potter has left room for educators to encourage conversation in students about the stigmas and implicit biases that people may hold about those with disabilities: that wheelchairs are only for those who are paralyzed or who have limited use of their legs, that some people may feign disability for personal benefit, that all disabilities are outwardly visible, and more.

Potter was diagnosed in 2016 with Postural Orthostatic Tachycardia Syndrome (POTS), a form of dysautonomia that causes her chronic pain, digestive difficulties, and difficulty controlling her breathing and heart rate. Dysautonomia, and POTS itself, is likely to be familiar to some students, as its rates have increased drastically in the population due to the COVID-19 pandemic (Dysautonomia International, n.d.; Fedorowski & Sutton, 2023). Furthermore, POTS is, to many, an invisible disability, meaning that it is not always outwardly apparent to others. Potter discusses at length the implications of living with an invisible disability ("You have no idea what someone is going through, and disability is not defined by what you can see on the outside"), including one instance in which her invisible disability led to an encounter with campus police. This encounter, while tragic, can open important classroom conversation about how the intersecting identities of those with disabilities impact their experiences.

While addressing some of the many difficulties that she faces as a result of her disability, Potter importantly addresses one key benefit—that it focused her attention to a need for a greater understanding of accessibility and disability rights. She addresses the way in which policies often undermine those with disabilities,

and she describes in detail the ways in which stigma impacts those in the community. From this, she makes a strong charge for those watching to become allies. She argues, "In order for abled people to be our allies, we must break the stigmas together!" Later, she continues, "Stigmas are wrong and ableist, and before any work gets done to change them, we have to change our minds first. Once that's done everything else is possible."

Thus, this video, while brief, can provide students with an important first-hand account of the ways in which disability can impact the experience of a college student. It can encourage discussion of invisible disabilities, intersectionality, stigma, allyship, and more. I have included below some suggested questions to encourage class discussion, but certainly the video would lend itself well to a wide range of other important conversations.

Questions for class discussion:

- In what ways are you oppressed? In what ways are you privileged? How might your intersecting identities influence this level of oppression/ privilege? How might your disability status, specifically, influence this?
- In what ways do you think Potter's interactions with the police were influenced by her intersecting identities? What may have happened in her encounter if she was a black man?
- In what ways might our campus be inaccessible to Potter? (Think about the inside and outside of buildings, availability of medical care and accessible transportation, and more)
- In what ways might our campus be inaccessible to community members with other disabilities? Consider here both visible and invisible disabilities as well as both the physical and virtual learning environments.
- What is involved in the process of receiving a disability accommodation at our university? In what ways may this process present barriers that discourage those with disabilities from pursuing accommodations?
- What might it look like to be an ally to those in our campus community who have disabilities?

Joyce: Disability, Not Invisibility

References

Dysautonomia International (n.d.). *What is dysautonomia?* http://www.dysautonomiainternational.org/page.php?ID=34

Fedorowski, A., & Sutton, R. (2023). Autonomic dysfunction and postural orthostatic tachycardia syndrome in post-acute COVID-19 syndrome. *Nature Reviews Cardiology*, 20(5), 281-282. https://doi.org/10.1038/s41569-023-00842-w