



Selected Papers of #AoIR2020:  
The 22nd Annual Conference of the  
Association of Internet Researchers  
Virtual Event / 13-16 Oct 2021

## RETHINKING VISIBILITY, PERSONALIZATION AND REPRESENTATION: DISABILITY ACTIVISM IN SOCIAL MEDIA

Nomy Bitman

Department of Communication and Journalism, The Hebrew University of Jerusalem

Social media provides marginalized activists multiple ways to create alternative narratives that challenge mainstream discourse. These narratives are generated using two central features of social media activism: visibility and personalization (Barrasi, 2018). The marginal identity's visibility is emphasized by activists' constructions of their networked identity, as part of a marginalized collective (Barrasi, 2018; Liao, 2019; Moors, 2019). Personalization is thus manifested by the activist's marginal identity's performance, based on an individualized personal storytelling strategy (Coudry, 2008; Vivienne, 2016).

Despite the greater freedom to express marginal voices in general, and the increasing accessibility of social media to disabled activists in particular (Ellis & Kent, 2017), disabled activists struggle in creating their counter-narrative within these platforms. These activists' inability to conform with inaccessible, able-bodied notions of activism (Ellis & Goggin, 2018; Trevisan, 2017) lead to their increasing participation in seemingly slacktivist practices, which provide accessible means for civic participation (Li et al., 2018; Halupka, 2018; Piat et al., 2019). From a theoretical perspective, disability activism is often discussed as separated from 'able-bodied' activism, and is often studied from a macro perspective that ignores its individual complexities (Trevisan, 2017).

This paper addresses these gaps by presenting the three stages of individual decision-making processes of users with concealable communicative disabilities regarding activist performance of disabled identity in social media. These stages follow the process from inception, considering disability activism, to its implementation – through performance of one's disability or avoidance of it. These stages were defined in the course of a thematic analysis of 31 in-depth interviews with autistics, stutterers and hard of hearing people who are active social media users, of whom seven also kept social media diaries for 48-72 hours. The focus on social media users with often-stigmatized disabilities provides new insights into the risks and complexities of contemporary social media activism.

Suggested Citation (APA): Bitman, Nomy. (2021, October). *Rethinking Visibility, personalization and representation: Disability activism in social media*. Paper presented at AoIR 2021: The 22nd Annual Conference of the Association of Internet Researchers. Virtual Event: AoIR. Retrieved from <http://spir.aoir.org>.

The first stage presents the interviewees' different *perceptions* of disability activism in social media. These perceptions mirror the inseparable connection between a person's self-perception as dis/abled, and one's perceived risk of performing a disabled identity in public. Experienced activists presented a stronger disabled identity by publicly performing their disability, which led them to perceive the impact of disability activism in social media as limited, practical and realistic. In contrast, interviewees who had a conflictual perception of themselves as disabled and abstained from taking part in disability activism, perceived its impact in idealistic, romantic, broad-reaching terms.

27-year-old Joe, a male stutterer, demonstrated the latter: "Let's talk about disability as a disability, and not as stuttering, okay? I think that concealable disability can be presented in campaigns which target audiences that mostly accept disabilities, and a minority that rejects it. This minority won't have the stronger voice, but rather those who accept the disability. Every society has both types. Those who reject disabilities are afraid of it. They don't know what it is. I think that once they understand, they will accept it."

The interviewees' perceptions led to the second stage: Interviewees' *motivations*. These manifested the interviewees' risk-benefit calculations when it comes to public disability exposure for the potential benefit of other disabled people, and the dynamic nature of disability activism on social media. The motivation of these interviewees to pay the high social price of risking their privacy through public exposure of their disability was to prevent children with their disabilities from suffering the social stigmatization, medicalization and isolation, experienced by themselves.

In addition, interviewees' motivations presented activists 'solutions' to users who wanted to take part in disability activism, but also to minimize their privacy risk. To protect themselves from the potential harm caused by disability stigma and context collapse (Marwick & boyd, 2011), many users expressed their own 'intermediate' forms of activist performances using private or semi-private spheres in social media.

The interviewees' perceptions and motivations were enacted through the *strategic design* of their activist performances and storytelling in both private and public spheres. These strategies were influenced by their constant awareness of the presence of their offline acquaintances in social media (Salisbury & Pooley, 2017). Younger interviewees, who 'grew up with Facebook' (Robards & Lincoln, 2020), had better skills and knowledge that enabled them to adapt their activist performances and storytelling to social media affordances and audiences, optimizing the resultant social benefit. In addition, many disabled activists' strategies reflected their own perceptions of disability activism as a social, 'neutral' matter, rather than a political issue.

The strategic design of activist performance also emphasized the centrality of personalization, visibility and representation. These elements are not only essential to social media activism in general, but also may be conflictual for activists with concealable communicative disabilities, given their diverse functioning nature and the potential stigma. It makes activism more complex for performers, as explained by 24-year-old Tom, an autistic man: "I have to think about which part of my group I truly

represent. Do I represent myself more than the whole group? I sometimes wonder whether the post that I write shows more of myself, the autistic group in general, Israeli autistics, or something else. It's different in each post."

The combination of social media studies and disability studies presented here, enriches the theoretical discussions of key concepts in social media activism research: representation, risk-benefit calculations, visibility and storytelling. The current paper reveals ableist assumptions behind both offline activism, which is often inaccessible for disabled users, and online 'slacktivism', that questions their commitment to activism, by illustrating the individual constraints and concerns disabled activists labor under. Such assumptions also have considerable effect on social media activism made by other marginalized groups.

## References

Barrasi, V. (2018). Social media activism, self-representation and the construction of political biographies. In G. Miekke (Ed.), *The Routledge Companion to Media and Activism* (pp. 142-150). Routledge.

Couldry, N. (2008). Mediatization or mediation? Alternative understandings of the emergent space of digital storytelling. *New Media & Society*, 10(3), 373-391.

Ellis, K. & Goggin, J. (2018). Disability and media activism. In Meikle, G. [Ed.], *The Routledge Companion to Media and Activism* (pp. 355-364). Routledge.

Ellis, K. & Kent, M. [Eds.] (2017). *Disability and Social Media: Global perspectives* (pp. 1-10). Routledge.

Li, H., Bora, D., Salvi, S., & Brady, E. (2018, April). Slacktivists or Activists? Identity Work in the Virtual Disability March. *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems* (pp. 1-13).

Liao, S. (2019). "# IAmGay# What About You?": Storytelling, Discursive Politics, and the Affective Dimension of Social Media Activism against Censorship in China. *International Journal of Communication* 13 (2019), 2314-2333.

Marwick, A. E., & Boyd, D. (2011). I tweet honestly, I tweet passionately: Twitter users, context collapse, and the imagined audience. *New media & society*, 13(1), 114-133.

Moors, M. R. (2019). What is Flint? Place, storytelling, and social media narrative reclamation during the Flint water crisis. *Information, Communication & Society*, 22(6), 808-822.

Robards, B. & Lincoln, S. (2020) *Growing up with Facebook*. Peter Lang.

Trevisan, F. (2017). *Disability rights advocacy online: Voice, empowerment and global connectivity*. Taylor & Francis.

Vivienne, S. (2016). *Digital identity and everyday activism: Sharing private stories with networked publics*. Springer.