**Disability Rights Movement and Social Media**

According to the World Health Organization and the World Bank (2011), one in five people will become disabled in their lifetime and over one billion people are currently living with a disability. There are many risks associated with being disabled. One is the higher mortality rates and 50% greater chance of being pushed into poverty due to high medical costs. There is also lower school attendance rates for children with disabilities and a greater chance of being chronically poor due to lack of employment opportunities and mobility. Disabled children are more likely to be abused and disabled women are more likely to face sexual victimization. In a recent study of Autistic people found 78% had been sexually victimized compared to only 47% of non-Autistic people! Four out of five disabled people live in low income countries that limits their access to care, and also limits their ability to participate in the global movement to change their conditions as many of them do not have the benefit of accessing social media as up to 80% of the world does not have internet access (Cook, 2011). However, the spread of social media and access to the internet has contributed significantly to the global disability rights movement that is putting pressure on people all over the world to address the needs and concerns of disabled people.

Raising awareness about disability, challenging stereotypes about the disabled, and advocating for the needs and rights of disabled people are all aspects of the Disability Rights Movement. The Disability Rights Movement is a global movement to solve social problems faced by those who have disabilities or identify themselves as Disabled. The Disability Rights Movement is made up of Disabled people and their allies and they are an inclusive movement across various forms of disability and they attempt to be an intersectional movement that works to expose and understand the ways in which other identities intersect with disability, such as race, gender, and sexuality. This paper will discuss the various components of the movement, offering a brief history and explanation of each component and highlight how social media have enabled, enhanced, and moved the movement forward across global spaces.

I have drawn on both traditional academic sources for the systematic research and analysis portions of this paper and I have drawn on non-traditional sources, including blogs, opinion pieces in the newspaper, and organizational documents to provide the background to the movement, snapshots of the movement online, and to represent the voices of the activists themselves. Academic articles provide systematic evidence to support claims and document the history of the movement and are considered more reliable sources. However, when you write about a marginalized group that is deviant, particularly a group that is challenging the dominant discourses about them, it is important to include non-traditional sources of information, especially the voices of the people themselves. They may be biased and self-interested, but self-representation is important. Furthermore, a paper on social media as a tool for a social movement, necessarily needs to include examples from social media. I rely heavily on these new media forms for examples to illustrate the points made in the more traditional literature.

As a member of the disability rights community myself, I want to note the language I will be using in this paper is Identity First language rather than Person First language. What this means is that I, as most other activists, identify as a Disabled Person, or in my case, as an Autistic and Disabled Person, as I have physical disabilities as well. The Person First language convention is popular among allies or those who subscribe to a medical model of disability and their point is that we are people first and not defined by our differences (for further reading, see Tobin, 2011). However, as we like to joke in the community, you wouldn’t say “a person with blackness/melanin” or a “person with femaleness/maleness” when that part of themselves is part of their identity, and part of the disability rights movement has been to claim the identity and take pride in our differences (for more on this, see Brown, 2011). Thus, I will refer to people in the movement as Disabled People and their allies rather than “Person with a Disability.”

**Consciousness Raising, Networking and Organizing**

A key component of any social movement is for the people who are suffering from a social problem to identify their problem as social rather than a personal problem (Best, 2012; Newell, 1999). The early disability movement had physical markers that helped people recognize each other and share that they faced similar barriers to education, physical buildings, and other aspects of society. This is why early disability rights expansions in America and other high income countries tended to gain traction when large numbers of veterans came home disabled. Then in the 1960’s, during the civil rights movements, the disability movement piggy backed on the notion of equal rights and parents started demanding that their disabled children be moved out of institutions and be included in schools. Parent advocates led the movement to gain legislation for educational rights for disabled children and disability self-advocates fought for barriers to be removed from buildings and social institutions, which finally was implemented into the Americans with Disabilities Act or ACA in 1990 which requires businesses and organizations to provide reasonable accommodations to disabled people (American Defamation League, 2017).

However, the disability rights movement, unlike many other movements, is not characterized by many direct actions. There were lobbying efforts and some small demonstrations, but perhaps due to the features of the disability itself, direct actions are not always possible (Newell, 1999). The onset of new media, argues Pearson and Trevisan (2015), allowed non-elites to be creators of stories, insert new discourses about disability into mainstream online sites (such as Huffington Post), and allowed marginalized groups greater visibility which gave them increased power to have a voice in policy making decisions as they could mobilize supporters to challenge elites. It also helped the disabled recognize that current institutions that were supposed to be advocating on their behalf were not serving their best interests, which spurred desire for change. Online communications made help available in a new form as people similarly situated could help others navigate social services, problem solve, and support one another, helping people realize that their struggles were not unique to them, but shared among members of the disabled “class” in society (Finn, 1999; Morris, 2013).

Social media, then, helps people form identities around their shared characteristics with increasing numbers of people being able to give both positive and negative feedback about the “self”(Holmes and O’Loughlin, 2012). To a person who is often isolated from others who are like them or where their identities are often kept secret to “pass” in the larger society, social media allows people to connect with those who can reflect their true selves and strengthen their sense of self as valued and worth social investment. Obst and Stafurik (2010) found that online participation increased well-being and personal growth, which may translate into new feelings of agency encouraging further explorations of new media (see also Bowker and Tuffin, 2007). Social media also helped with knowledge diffusion about the accessibility of various locations and allow for the disabled to alert fellow disabled people of discriminatory experiences faced in businesses and other locations (Altinay, et. Al., 2016).

New forms of technological communications across social media enabled small groups of activists to make connections globally to exert pressure on representatives across several countries which led to many successes in gaining supports across national boundaries (Pearson and Trevisan, 2015). In a study of the intellectually disabled, Caton and Chapman (2016) found that social media enhanced self-esteem and created a positive sense of identity, but that concerns over safety, digital literacy, and the rules of digital citizenship remained. However, these are similar concerns that the disabled have faced in real life interactions as well.

One of the best advantages of social media for the disabled is that they were in control of how and when to disclose their disabled status, tell their story, so they could build relationships or play games and interact with people without the pre-judgments of the other person (Furr, et. Al, 2016; Bowker and Tuffin, 2007). This ability to be “in society” without the prejudices of disability is one reason why online gaming with avatars is particularly popular among the disabled as well. Avatars can be any gender, any race, and can be able-bodied, allowing people to experiment with their identities, experience social interactions free of social constraints, and allow them to live various fantasies they may have (Stendal, et. Al, 2011). While this may seem counter-productive to the disability rights movement that encourages people to re-claim their disabled identity and fight against ableism and social barriers, the process of stepping out of your social status and experiment with various social roles may help the person imagine a world where they could be treated as equals and fully participating members of a society and can challenge their own internalized oppression by allowing them to demonstrate full competence in an online environment and therefore more willing to demand the presumption of competence from other people in real life settings. While it may not lead to activism, more social successes and experiences that challenge the dominant paradigms for disabled people set the foundation for further activism. A saying among disabled activists is that merely being alive in a world that devalues you is a political statement in and of itself and challenges the dominant paradigm.

The development of personal computers, the internet and now social media have accelerated and expanded the movement as it is easier to find people like you and connect over great distances and using technology to get past language or physical barriers (Pearson and Trevisan, 2015). Prior to social media and the internet, the disabled met in summer camps, rehabilitation centers, and colleges and met some of these same goals, but was restricted to those with the financial means to access those. the spread of social media and the internet made these social, psychological, and political tools available to a larger group of disabled (Patterson, 2012).

https://ollibean.com/privacy-versus-popularity/

Social media has also exposed fault-lines within the communities of activists. One of the main battles being fought in the disability community is between parent-led advocacy groups that often define their child’s disability as a deficit and adult self-advocates who are themselves disabled. This is a particularly heated battle within the autistic community where self-advocates promote neurodiversity which defines autism as a brain difference that should be equally valued and parent advocates promote neuro-inclusiveness but define their child’s autism as a disorder/deficit in brain capacity that is in need of treatment or a cure. Also between parents and disabled adults is the battle over privacy for disabled children. Amy Sequenzia is a well-known activist who argues passionately that disabled children deserve to have their privacy maintained and respected and that it is not the parents’ story, but the child’s.  This battle is being fought globally, at least in Western countries (Bertilsdotter Rosqvist et al., 2014). However, this contested terrain over the meaning of disability and who gets to control the story of their lives really arose due to the growing availability of the internet and social media where autistic people, with varying degrees of verbal language skills could connect with each other, share experiences and make meaning of those experiences under the umbrella of autism, for example, and start challenging the dominant discourses by parent led groups. Social media is also strengthening the connections between various disabled groups who are fighting similar battles over autonomy, privacy, and the meaning of disability. Underlying this tension is what Bertilsdotter Rosqvist, et. Al (2014) say is the reformist goal of the parent led advocate groups that seek therapies, cures, and education that will teach their children to fit within the non-disabled/neuro-typical framework of society contrasted with the disabled self-advocate goals that are fighting to be accepted as they are.

Pearson and Trevisan (2015) categorize three main ways that new technologies have enhanced the disability rights movement. The first is through existing advocacy organizations, often led by parents and/or professionals that tend to use new technologies and new media as boosts for their fundraising campaigns, for their awareness campaigns and to increase membership in their organization. Some of these are inclusive of the disabled and many high profile ones are not. In the autism community, many activists are outright opposed to one of the largest autism organizations: Autism Speaks. They argue that they raise money to find a “cure” which pathologizes Autistics and they do not include autistic people in their organization except as rare tokens. So while new media has helped raise the visibility of some of these organizations, they also open them up to criticism and push back by Disabled activists. The second way new media has enhanced the movement is by experienced activists who were part of the social movement early and created an online presence connecting with those they had met with at various actions. These activists and self-advocates used the social media framework to continue their work independent of entrenched organizations. The third type highlighted by Pearson and Trevisan (2015) are the new activists who started blogging and connecting through social media finding their voice and creating online only actions which included petitions and viral campaigns to spread their message. Drawing on other movements where the “personal is political,” these activists started living their lives more publicly online and built up the momentum that grew beyond the initial consciousness raising and awareness campaigns to full-fledged movement to change the discourses on disability and fight for full inclusion in every sector of social life. While the voices of the disabled are often trivialized, discounted and ignored, new media has enabled them to reclaim their voices (Newell, 1999).

2https://secure.polyvoreimg.com/cgi/img-set/cid/151958660/id/LuYSss7G5BGJWym07EzHKw/size/y.jpg

**Fighting for Inclusion, Reducing Barriers and Promoting the Social Model of Disability**

The main slogan for the global Disability Rights movement is “Nothing about us without us” (Winter, 2003; Bell, 2014). This is the rallying cry of full inclusion into all aspects of society, especially those aspects that are explicitly about those who are disabled, from medical care decision making, public policy decisions, educational decisions, and even the right to have a say in their living and caretaking arrangements, even when provided by family members. The main component of this aspect of the movement it to change the conception of disability as a medical condition and personal problem to an understanding of the social model of disability which states that the majority of “problems” faced by the disabled are social in nature and can be remedied with social changes (Ne’eman, 2009).

There has been some global progress on the rights of the disabled. The International Year of Disabled Persons was 1981 (Newell, 1999). In 1990 the Americans with Disabilities Act was made into law requiring that businesses and other organizations make reasonable accommodations (Cook, 2011). In 2006, the UN and 175 member states signed a global treaty on the universal rights of the disabled, called the Convention on the Rights of Persons with Disabilities (Cook, 2011). In the 2008 US presidential election, there were efforts by both sides to court the disability vote, a sign that the movement’s presence was being felt (Ne’eman, 2009). In 2011, the World Health Organization and the World Bank jointly published the first World Report on Disability that reported on the status of disabled people around the world (Cook, 2011). This is progress, but it is still not translating into any real changes for Disabled people.

The online fight to challenge the bio-medical model of disability to a social model of disability sets the tone for how the disability rights movement organizes itself around issues of work, education, and housing, but it also, according to Parsloe (2015), helps the disabled themselves “reclaim normalcy, symptoms, and agency (p. 336)” and fight the internalized oppression that can come from adopting a bio-medical model that suggests you need to be cured and you are not okay as you are. It allows the disabled to stop blaming themselves for social barriers. However, as Parsloe (2015) found in her study with Autistics, they often still shifted their “selves” from being part of the neurodiverse community and part of the neurotypical community that they had been raised to fit into.

**Raising Awareness, Raising Pride and Resisting Social Discourses**

Unfortunately, the internet is rife with “feel good” stories about disabled people who don’t need any help and can do anything no matter what the barrier and stories of non-disabled people coming to the rescue of a disabled person by including them to eat lunch with them or throw the last basketball or any number of stories that lend themselves to viral social media stories. This type of myth making story about the disabled is referred to as “inspiration porn.” As Hadley (2016) found, there are three types of memes that are spread through social media about the disabled: the inspiration, the charity case, and the cheat. Each of these memes encapsulate the dominant narrative about the disabled that the global movement for disability rights attempts to disrupt and challenge. These dominant stories tend to force the disabled into performing their selves to fit within or counter these myths in order to get life-saving care and access to social institutions that they need.

The first one, the charity case, is meant to elicit help, rescue, and support for some poor person. This is often children or people who have found themselves suddenly disabled. The problem with this type of meme is that it reinforces stereotypes that the disabled are needy, dependent, and weak (Hadley, 2016). This is counter to the message of the movement that attempts to push the narrative to presume competence when interacting with a disabled person. Presuming competence means that you presume the person can understand you, learn, and problem solve even within their limitations (Zurcher, 2013). A common trope is the neurotypical team members or child who “heroically” makes friends with the disabled person as if the disabled person isn’t worth a friendship without the non-disabled people’s largesse, which many find patronizing and condescending. If you presume that the disabled person would make a terrific friend, then there is no hero just making friends with them or inviting them to eat lunch with you. These memes only make sense if you buy into the idea that no one would be friends or partners with a disabled person. This can be internalized by Disabled people or it can force people to feel like they have to be grateful for patronizing behavior towards them and not enforce personal boundaries or make other demands as they only have this “friend” because they are dependent. Liddiard (2014) argues that these memes, or cultural images of disabled people, are commodified in social media where people are literally profiting off of the pity likes or concern likes, reducing images of the disabled into tradable goods. She argues that disability scholars and activists have yet to seriously take on this challenge of how disability representations are reproduced over and over again as they are shared all over various social media platforms.

https://disabledidentity.wordpress.com/2016/04/27/pity-and-the-prom/#comments

Another large part of the online presence of disabilities that is challenged by the Disability Rights movement is what we call, “inspiration porn” which are memes and images that stress the “no excuses” model or the memes that suggest only bad attitudes are disabilities. It is very victim blaming and dehumanizes the disabled person. The obvious problem with this model is that it forces the disabled to not ask for help when they need it, to hide their disability in an attempt to pass and to always smile no matter how you get treated; the onus is on the Disabled person, not society, to overcome any challenges, with a smile, of course (Hadley, 2016). As one activist states, *“*[*Inspiration porn is when disabled people are called inspirational or brave for doing all the things that regular people do.  It’s a problem because it assumes that anyone with a disability must have it so much worse than the rest of us.  And because it uses disabled people to make us non-disabled people feel good about ourselves, or to make us do something, like exercise or whatever.  And disabled people aren’t tools, they’re people (thefaultinourspoons, 2014).*](http://t.umblr.com/redirect?z=http%3A%2F%2Fthatcrazycrippledchick.blogspot.co.uk%2F2014%2F01%2Fexplaining-inspiration-porn-to-non.html&t=NWI0M2IzN2VlYWZiYWIxZjY3MjFkNWJjZDIzNDUyMmYwODZkYWZlNSw4Q2tva3Btdg%3D%3D&b=t%3A6uto7kWpvVzSUgCHJKtjWw&p=http%3A%2F%2Flivingwithdisability.tumblr.com%2Fpost%2F86681705513%2Fthefaultinourspoons-inspirational-porn-is&m=1)*”* Liddiard (2014) refers to these images of “supercrips” as particularly harmful as they disguise the structural, cultural, and environmental causes of the barriers faced by the disabled.

http://68.media.tumblr.com/c6f1ebdb6d1d3a89e3092378d4fac0b8/tumblr\_n611vsXtvu1rn5dgao2\_1280.jpg



The final meme of disabled people fits within the theme of “worthy disabled” who need supports and “cheats” and liars who are just claiming it for the parking pass, government benefits or personal financial gain. There are ones that body shame and say disability equipment (such as a parking pass or wheelchair) is for “real disabled” not fat people, as if the disabled don’t become overweight from lack of mobility. This meme forces disabled people to be nervous to use resources, afraid of being attacked as several have reported happens with use of the placard for parking. People have been accosted, had police called, and all sorts of gestures of non-belief, putting the onus on the disabled person to share their medical history. As the meme here demonstrates, people assume that all wheelchair users are paralyzed vs. chronically ill and can only walk or move short distances. The photographer here and meme creator don’t know this woman’s story, but it fits the myth of disability cheats. The use of these memes is to police those who are not deemed worthy enough to be considered disabled and ensure that fat and lazy people don’t get a pass (Hadley, 2016). Again, Liddiard (2014) reminds us that the focus on cheats and non-deserving disabled enables the austerity policies that are sweeping high income nations and have been linked to increases in hate crimes against the disabled, thus having dangerous consequences to the disabled, not mere offenses against our sense of selves in the cultural arena.

http://www.dominickevans.com/wp-content/uploads/2013/12/AlcoholicMiracleDisability.jpg

Finally, the disability rights movement attempts to challenge public shaming and ridicule of those with disabilities. From the campaign to end the use of the word “retard” and other ableist language, to sharing stories so that people understand the real struggle of those with disabilities. Social media allows people to combat public shaming as the woman in this photo did in her post titled, “I am the woman in this picture and this is what it was like (Wilkinson, 2016).” In her narrative, she tells her story and describes her disability and turns the shame back to the onlookers who took photos rather than help her and to viewers who consume her body without her consent. In many of these challenges, the person talks about the combination of fat shaming, body shaming in general, disability dehumanization, and mental health disabilities (Hadley, 2016). Taking photographs of the disabled without their consent has become a big market in social media. Sometimes it is pictures of people in their daily lives and sometimes they are stolen photos that get revised and purposed to bring profit. Liddiard (2014) points out that unlike in previous times where “freaks” were able to garner profit for themselves by doing shows with carnivals and the like, now people steal photographs and create fake stories that typically reinforce the dominant discourses of the disabled and either generate likes for cash or link to fake charitable organizations to fraudulently claim your pity money. It is also notable that social media has allowed for the proliferation of groups, such as Facebook groups, that are titled and purposed to target various groups of disabled people, particularly those with intellectual or neurological differences and that Facebook has refused to shut those sites down claiming they do not violate community standards, unlike female nipples (Liddiard, 2014).

https://www.indy100.com/article/i-am-the-woman-in-this-picture-and-this-is-what-it-was-like-7444991

They also routinely dissect and analyze media representations that can fuel or challenge disability stereotypes both in traditional and social media. However, as Hadley (2016) point out, these challenges are regularly dismissed by the general public as being somebody else’s personal problem rather than something they should be concerned with and the risk is that the online challenges made by disability activists only circulate among themselves. To combat this issue, disability activists have started generating their own memes which often take popular memes and turn them on their head, invert their logic or use them for their own purposes, which is called *culture jamming* (Hadley, 2016; Liddiard, 2014). Culture jamming is both a resistance practice and a community building practice whereby people build pride and share their humanity with the world. A good example of this is the #disabledandcute twitter trend where Keah Brown started a viral campaign to demonstrate how you can feel cute even while being disabled, which is often associated with being ugly (Goldberg, 2017).

http://www.self.com/story/disabled-and-cute

**Continuing Battles**

While the picture of the disability rights movement online seems widespread and impactful when you use online resources to describe and understand the movement, some research on Facebook use of the disabled and other similar forms of social media finds that most disabled people are not using these social media apps to do political work or even create new content, but are primarily using it to connect with their existing social ties, similar to non-disabled users (Shpigelman and Gill, 2014). However, many reported using other sites that were perceived as safer and the potential is there and it is growing, so activists need to tap into these users and mobilize them to join the activist community if they want to have even greater power to influence policy.

Media representations and stereotypes of the disabled all over the world continue to be a major barrier to employment and acceptance for the disabled (ADL, 2017) and while the ADA is full of promise, in practice, enforcement is spotty and there are still many gaps. Recently I was trying to work with an organization connected to the school district who insisted that the ADA did not apply to them, even after I called the Attorney General’s Office and was assured that it did apply to them. The lack of awareness by people who are supposed to be ensuring inclusion for the disabled is only one of the ways in which the law fails to provide equal protection (ADL, 2017).

There is still a digital divide in many countries due to poverty and the disabled still have limited access to the internet and new media compared to the non-disabled. This is worse in lower income countries, so there is still a lot of progress that needs to be made to make sure all disabled voices are included in the movement and in the leadership of the movement (Pearson and Trevisan, 2015; McCarthy, 2003). One success of the movement has been the inclusion of non-verbal and partially non-verbal people who are able to use augmented communication devices and apps to participate online (Hynan, et. Al, 2014).

There is still much work to be done, however, to be truly intersectional across disabilities and across other forms of oppression. As Meekosha (2002) argues, women with disabilities are not seen as real women and not seen as real disabled and are much more likely to be sexually victimized. She articulates the need for a combined feminist and disabled critique of the traditional norms of passivity and dependence for both women and disabled people. Davis (2015), a transgendered autistic person, cites the double inaccessibility they face and White (2016) has suggested that autistic people who are transgendered are being denied medical treatment as it is assumed they cannot make this type of choice for their body. Race and disability intersections are particularly complicated as there are ways in which disability is underdiagnosed or diagnosed late, such as with neurological differences, but there are ways in which disability is over-diagnosed in schools where kids who are leading chaotic lives are shoved into emotional and behavioral classrooms rather than understanding their social circumstances. Over half of the people in correctional institutions have some form of disability and are disproportionately people of color and half of police involved shootings involve a disabled person, many of them disabled people of color (Hing, 2015; Perry and Carter-Long, 2016). Thus, the picture of disability is much more complicated than has yet to be addressed by the movement outside of sharing stories on social media and boosting the signal of important papers such as the Ruderman White Paper (Perry and Carter-Long, 2016).

The fight for the disabled to live their lives outside of institutions and be fully included in social life is an ongoing fight, a fight characterized by Ne’eman (2009) as one of empowerment, independence and self-sufficiency (see also Newell, 1999). There has been concern over the past few decades with advancements in technology and medicine increasing the pressure to be fixed until you are perfect and the costs associated with the aging populations that may lower people’s compassion as we are seeing played out in our national political discourse over healthcare. It is not a new concern, but the fears expressed by early movement leaders seem to be playing out in many ways (McCarthy, 2003).

As the movement continues, it is important that people draw on the knowledge of traditional academic work inside and out of disability studies to avoid the pitfalls of early leaders and build on the strengths of what works for the disabled community. These studies, however, are often limited by disciplinary silos that don’t talk to each other much and small sample sizes that make them difficult to generalize. They also tend to draw on their samples from high income countries so that the picture of what life is like for disabled people is often skewed. Studies that include disabled populations in the Global South are particularly rare (with the exception of Australia and New Zealand). It is equally important to draw on the knowledge of the lived experiences of those who are disabled as they portray themselves, not filtered through academic paradigms. Searching online also allows you to see current debates, current campaigns and current understandings of what it means to be disabled and what barriers are faced by disabled people who have access to the internet. Unfortunately, the vast majority of disabled still do not have steady access to social media and therefore we need more studies from the World Bank and World Health Organization or reports from the United Nations that are able to compile information and data across a wider cross-section of the disabled. The future of the movement depends on drawing in more people and the future of disability studies needs to be inclusive of more disabled voices.

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