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Research Paper

Self-representations on social media. Reproducing and challenging discourses on disability[★]

Représentations de soi sur les réseaux sociaux. Reproduire ou défier les discours sur le handicap

Coppélie Cocq^{a, *}

coppelie.cocq@helsinki.fi

Karin Ljuslinder^b

karin.ljuslinder@umu.se

^aUniversity of Helsinki, Helsinki, Finland

^bUmeå University, Umeå, Sweden

*Corresponding author at: University of Helsinki, PO Box 59, Unionkatu 38, FI-00014, Helsinki, Finland.

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Abstract

This article examines self-representations in a social media campaign against the discrimination of people with disabilities. We focus specifically on how these representations are related to various narratives and discourses, and in what ways the representations either adhere to or challenge normative discourses, or whether they offer counter-discourses. Considering that our cultural assumptions are influenced by the representations we are exposed to, we also discuss the possible potential of self-representations for the audience of the campaign. The empirical material consists of a digital activism campaign conducted on Instagram in Sweden that was constructed through self-representations (photos and short texts). The study combines discourse analysis and visual analysis with focus on how the persons present themselves in the campaign, how disability is mentioned and/or displayed, and how a presentation adheres to or challenges a model of understanding disability, such as the medical or social models. We found a diverse set of claims, all with the common goal of acknowledging discrimination, in order to make it visible and bring about change. The narratives identified indicate a variety of strategies for understanding disability and various styles that people adopt to relate to established discourses on disabilities. Through this campaign, the bloggers could find and provide support, but they also took the stage by requesting that the audience listen. The campaign examined in this study can be further understood as an effort and a step towards increased visibility and politicization of disability.

Résumé

Cet article analyse les représentations de soi dans une campagne menée sur les réseaux sociaux contre la discrimination des personnes handicapées. Nous nous intéressons plus particulièrement à la manière dont ces représentations sont liées à divers récits et discours, et à la manière dont elles

adhèrent ou défient les discours normatifs, ou encore offrent des contre-discours. Étant donné que nos représentations culturelles sont influencées par les représentations auxquelles nous sommes exposés, nous discutons également les représentations potentielles de soi que cette campagne propose à son public. Notre matériel empirique est constitué d'une campagne d'activisme numérique menée sur Instagram en Suède en 2016 et construite à partir d'un ensemble de représentations de soi (photos et textes courts). La recherche combine analyse du discours et analyse visuelle en mettant l'accent sur la manière dont les personnes se présentent, dont le handicap est mentionné et/ou présenté, et dont une présentation adhère à, ou conteste, un modèle de compréhension du handicap, tel que le modèle médical ou le modèle social. Globalement, nous trouvons un ensemble diversifié de revendications, toutes ayant pour objectif commun de reconnaître et de rendre visible la discrimination, et d'apporter des changements. Les récits identifiés montrent la variété de stratégies adoptées pour comprendre le handicap et les diverses manières dont les gens se rapportent aux discours établis sur le handicap. Grâce à cette campagne, les blogueurs ont pu trouver et apporter un soutien, mais ils ont également pris la parole en demandant au public d'écouter. La campagne examinée dans cette recherche peut en outre être perçue comme un effort et un pas en avant vers une visibilité et une politisation accrue du handicap.

Keywords: Discourses; Narratives; Digital activism

Mots clés: Discours; Récits; Activisme numérique

1 Introduction

The contemporary media landscape, with the increasing omnipresence of internet access and mobile technologies, has been seen by many scholars as a possible promoter of democracy (Graber, 2003; Livingstone & Markham, 2008), and is praised for opening up civil participation and bridging the disability gap (Guo et al., 2005; Ritchie & Blanck, 2003). Optimistic and sometimes utopian perceptions regarding the internet (Finkelstein, 1980; Ritchie & Blanck, 2003) have also been contradicted, however, and research suggests that the democratic participatory effects of social media are limited, not least because one needs both access to social media and personal skills to handle social media in order to be able to use it (Barlott et al., 2019; Lussier-Desrochers et al., 2017). Scholars have demonstrated that we should not underestimate the potential of social media to maintain and consolidate excluding structures, and discourses should not be underestimated (Dean, 2003; Fuchs, 2014; Hindman, 2009; Ineland, Gelfgren, & Cocq, 2019; Morozov, 2011).

Previous research has also analyzed the role of media in general, as it is not restricted to digital media in shaping, maintaining or challenging representations. Media are perceived as central to a societal understanding of disability. For example, Farnall & Smith (1999) demonstrate that portrayals of people with disabilities in the media have implications for the perception of disabilities. Kenix (2011) claims that our understanding of each other, and our shared social notions, are based on continuous construction by the media. Furthermore, Varona (2004:1) describes the 'unparalleled influence' of the media in shaping our 'culture, identity and values'. Curran & Morley (2007), Hall (1997) and Hartley (2012) argue that media depictions are molded by hegemonic cultural values and cultural notions. As a consequence, these become common agreements and values of different phenomena and social groups. Even though reproduction and sharing of cultural values also occur in interpersonal communication or group communication, media images tend to become the most pervasive and far-reaching (re)producers of society's cultural values because we spend considerable time with media in our everyday lives (Ljuslinder, 2002; Hall, 1997). This applies in

particular to phenomena of which we, the audience, have little or no personal experience. The importance of media values and notions for the audience's worldview does not, however, amount to a simple, straightforward transfer from sender to receiver, but rather consists of a complex relationship in which the media reflect reality as well as shape it. This means, as a result, that if we as the audience are exposed to pathologizing stories of people with disabilities, this will probably also become our own perception of what disability entails.

This article investigates self-representations in a social media campaign against the discrimination of people with disabilities. We focus specifically on the representations of various narratives and discourses that relate to disability, whether these representations adhere to normative discourses or challenge them, and finally, whether they offer counter-discourses. We use the term narrative to refer to stories that the bloggers post and by discourses, we refer to a comprehensive, contextual view and understanding of how a certain phenomenon is made comprehensible (Laclau & Mouffe, 1985). Considering that our cultural assumptions are influenced by the representations we are exposed to, we also need to discuss the potential of self-representations for the audience of the campaign. Thus, we examine the interactions within the campaign and discuss how inreach and outreach communication operated during the campaign.

2 Digital media and disabilities

Digital media and disability have been considered among scholars as either a groundbreaking opportunity for societal inclusion and participation or as yet another way that people with disabilities are excluded from participation.

On one hand, the rapid development of digital media and modes of communication have equipped us all with new means and tools for societal participation. For instance, Pearson and Trevisan (2015) claim that what is referred to as the new media has enhanced opportunities for people with disabilities to increase their possibilities to have their words, stories and opinions disseminated instead of being merely consumers of media content (Tucker, Theocharis, Roberts, & Barberá, 2017). Goggin and Noonan (2007), Sheldon (2004) and Taubner, Hallén, & Wengelin (2017), among others, have claimed that forums and blogs are important for alternative representations of disability as a challenge to dominant representations. Studies have also reported that the Internet can be empowering for people with intellectual disabilities in terms of their self-expression, social relationships and presenting themselves as people first and not as disabled first (Chadwick, Wesson, & Fullwood, 2013). Moreover, Barlott et al. (2019) investigated the experiences of people with intellectual disabilities who used digital technology and determined that it played an important role in their social connectedness with others.

On the other hand, despite increasing knowledge of disability and design, new technologies are still not fully accessible, and people with disabilities can therefore be overlooked or neglected. New technology creates new exclusions, as Goggin and Newell (2007) observe. Chadwick et al. (2013) claim that not only technology excludes people with disabilities from the internet, but there are also political and economic factors combined with attitudinal behavior that marginalize people with disabilities from the internet. Scholars such as Goggin and Newell (2003), Ellis and Kent (2011), and Lussier-Desrochers et al. (2017) emphasize that a digital divide exists and that it continues to reproduce social exclusion and ableist oppression in the lives of people with disabilities. This is due to a lack of access and accessibility to digital technologies as well as the materiality inherent in

technologies based on assumptions regarding a certain body type. They refer to this intrinsic inaccessibility of technology as *digital disability* (Goggin & Newell, 2003).

To summarize, whilst research reports on the emancipatory possibilities of social media on one hand, on the other hand there is a risk that social media may reproduce social exclusion.

Whatever one thinks about digital technology, it has led to the emergence of various forms of digital activism, that is, ‘forms of activism that use the internet and digital media as key platforms for mass mobilization and political action’ (Fuentes, 2014). The Internet and social media have been identified by some scholars as alternative media (Lievrouw, 2011), owing to the wide range of channels they offer to organize and facilitate protests and resistance. However, the above-mentioned digital divide must be taken into account. It is also important to remember that the Internet, even though it has been associated with so-called revolutions in various geographical and cultural settings (Burns & Eltham, 2009; Jansen, 2010; Mungiu-Pippidi & Munteanu, 2009), ‘is only a tool, not a cause, of social change’ (Hill, 2013:14). According to Pearson and Trevisan (2015), two challenges arise in creating an impact with digital activism concerning disability. The first is the difficulty in reaching traditional news media, as they continue to exert considerable influence over political decisions. The second concerns the constant struggle to rebut cultural stereotypes and prejudices about people with disabilities.

Digital activist actions and campaigns by people with disabilities often utilize personal stories as a strategic tool to win over public opinion (Bennett & Segerberg, 2011; Pearson & Trevisan, 2015). Even though personalized activist actions have been criticized for creating a victimization narrative of disabled people, personal stories do indeed contribute to the politicization of disability as a subject position (Pearson & Trevisan, 2015), and a political framing of disability is indispensable for social change. Yet, in a society where the hegemonic understanding of disability is medical, disability is often removed from being political and essentially envisioned only as a fact of nature and not as a political position. As a consequence, there is no space for discussions and negotiation of what it means to live with a disability, which makes it difficult for social changes to occur (Kafer, 2013).

3 Material

The empirical material consists of a digital activism campaign against the discrimination of people with disabilities created by self-representations (photos and short texts) and conducted on Instagram in Sweden in 2016. The dataset includes presentations by ten different people who each contributed one to nine posts during one week each. The bloggers posted photos and short personal stories that presented themselves and their daily living. Seven women and three men, all young adults, participated by using the rotating curated account of the campaign¹. The material also includes an interview with the person who initiated the campaign and provides background information and more knowledge on the underlying intentions.

The account and concept were originally initiated as a private initiative by two members of a Swedish organization for people with disabilities, but it rapidly transformed into a campaign that included more people and perspectives,² expanding more than the initiators had expected. The initiators identified Instagram as a convenient channel to increase awareness of the discrimination against people with disabilities, as Instagram offers the opportunity to use both text and images and because it fosters interaction. This social media service is indeed a fruitful platform for this study. In the Swedish context, Instagram has been used as a central communication channel in several awareness campaigns through accounts created by institutions and shared with private individuals.

Instagram allows registered users to upload pictures and videos. Similar to other social media platforms, users can interact with comments, such as emojis, and “likes”. According to the national report on Swedes and the internet (Thoresson & Davidsson, 2017), Instagram usage has increased with more than half (53%) of all internet users in Sweden being on Instagram and almost a third (31%) using it on a daily basis. A popular method of conducting campaigns are rotating curated social media accounts that aim to increase knowledge and raise awareness. An example of this is the @IndigenousX account on Twitter (an Australian based account for raising awareness of Indigenous issues, see Sweet et al., 2013). Several other minor campaigns have also been conducted in the Swedish context through hashtags. Examples of these include #rockyoursocks, #becoolinschool, #minjävlarättighet [my damn right] and #assistansärfrihet [assistance is freedom] and the main objective of these was to encourage an understanding of disabilities.

The campaign selected for the purposes of this study is particularly interesting because a national association organized it and the people who participated represented a variety of voices. In contrast to other campaigns established by individuals, a campaign that is founded by a well-established national organization tends to have a broader impact and reach a larger audience. This association has branches in several regions of the country and has increased visibility through several campaigns. This particular association has also engaged in the public debate on many occasions on issues pertaining to people with disabilities.

The aim of the campaign was to increase awareness and disseminate information among non-disabled people about the discrimination that people with disabilities experience in their daily life. The rotating account was therefore used as a communication channel used by individuals with various experiences to share their thoughts and perspectives.

The target group, people without disabilities, was addressed directly in the description of the account:

‘Do you have a normative functionality³? Take a step back and listen! We are activists in politics about functionality and disabilities. That is all you need to know’.

By presenting the collective group behind the account as activists, the campaign clearly sets the agenda and the participants frame the content of the posts.

The participants who used the rotating account were invited as guest bloggers because they ‘had a lot to say and an interesting story to tell’.⁴ A number of people displayed interest and applied to participate, and a few were selected by the project leaders. According to the campaign leader, the account received positive reactions from members of the organization and the campaign resulted in ‘lots of knowledge and good stories’.

4 Methods

To examine and analyze self-representations in the selected material, we combined discourse analysis and visual analysis. We focus on how the persons present themselves. This includes information on if, when, and how the disability is mentioned and/or displayed, and if and how a presentation either adheres to or challenges a model of understanding disability, such as the medical model or the social model. These different models of understanding disability, which we mean co-exist, not only create various definitions of disability, but also provide explanations of causal attribution and responsibility attributions, guide the formulation and implementation of policies, and contribute to the creation of people with disabilities’ self-identity (Retief & Letsosa, 2018). The

dominant explanatory model continues to be the medical model. Other co-occurring explanatory models in our contemporary society are predominately based on the social model.

For the purpose of this study, we mean that the models for understanding disability can be described as synonymous with discourses, meaning a structured totality, a comprehensive view and understanding, which entails how a certain phenomenon is made comprehensible and talked about (Laclau & Mouffe, 1985).

For the discourse analysis, the concept of discourse is naturally the primary focus. We apply this concept of discourse in our study to identify specific ways of presenting oneself that adhere to different disability discourses or that counter discourses. For example, one can characterize one's situation in two different types of discourses: either as having a disease or as being prevented or hindered from participating in society as a result of social structures. The first is referred to as the *medical discourse, or model*, and the second is referred to as the *social discourse, or model*. Our analysis applies the analytical tool of *articulation* (Laclau & Mouffe, 1985), that helps us understand the connection of the sign “disability” to other signs in a presentation. It is this connection that is defined as the articulation, that is, how different signs are interconnected and attribute meaning to one another in a long chain of meaning, the discourse. The articulations of signs are fundamental in understanding the construction of meaning (Howarth, 2005). Through discourse analysis, we analyze the socio-cultural views concerning the meaning of disability.

The visual analysis (Lister & Wells, 2001; Mirzoeff, 1998; etc.) includes a study of the composition, aesthetics, and genres of the photos and what they represent denotatively and connotatively in terms of what they depict, as well as the associations they create. For instance, a selfie taken by a smartphone evokes other associations than a professional portrait would, and as a consequence, the distance or closeness to the addressee can vary. The visuals are analyzed in relation to the posts, as a photo can create, strengthen or exemplify a personal narrative, or merely be a generic illustration. When combined, these approaches on discourses and visuals assist us in identifying which narratives are shaped and conveyed. By narrative, we refer to the accounts that emerge from the short blog posts at the level of personal narratives in relation to dominant discourses (Andersson & Cocq, 2016; Hammack, 2011). This includes the subject position from which they are constructed and through which models of understanding disabilities the bloggers present themselves.

Several ethical considerations needed to be addressed in this study. We decided not to quote, display, or explicitly refer to singular posts and photos. Instead, we present a synthesizing analysis of the contents of our materials, followed by a thematic categorization of the narratives that were identified. This decision is motivated by the sensitivity of the topic and the potential vulnerability of persons involved. This study focuses on the narratives rather than on specific persons and we therefore consider that the richness of the material remains despite the measures we have adopted to protect the confidentiality of individuals in our data. These strict ethical considerations are in line with practices and recommendations in internet research (Markham & Buchanan, 2012; Franzke et al., 2019:11) and is based on a careful examination of the benefits of the study in relation to the risk of harm to research participants.

Within this ethical framework and in respect for the participants, we have striven to provide a reliable and accurate description of the materials. In some cases, in order to better illustrate the narratives, we provide some “fabricated” examples (Markham, 2012:334) of Instagram posts based on the material in our study. We are conscious of the loss of nuance and individual variation, as well

as the risk of generalization that this might imply but hope to have reached a balance between the specific and the general in our approach and analysis of the voices in the material.

The following section explores whether the narratives and aesthetics either adhere to or challenge dominant discourses on disabilities.

5 Narratives and aesthetics

All guest bloggers presented themselves with photos displaying their faces or their bodies. Their presentations followed with general personal information and what could be described as an informal CV. Most of them preferred to introduce their non-normative functionality as secondary, that is, what came first was their age, the city they lived in, their jobs and interests, etc. As an example, ‘Hello, my name is Kim, I am 25 years old. You are welcome to follow me this week; I will show and tell you about my daily life’⁵.

Some posts introduced disability as a disease or as a diagnosis. Sometimes, no mention of the disability was made but was represented connotatively, as by a detail in the photo such as a wheelchair, or a sign (logotype or name) that indicated participation in an organization for the rights of people with disabilities.

The material consisted of a high number of selfies, or portrait photos taken with what appears to be a phone camera, which served as a snapshot of a moment. When people compose portraits and selfies, they often looked directly at the camera, establishing a sense of contact with the reader/receiver. The photos illustrated various methods and degrees of being personal. For example, this was achieved by either looking directly at the camera or not, being close to the camera or not, exhibiting facial expressions or not, etc. Here the closeness and feeling of co-presence that was created also helped to strengthen the feeling of authenticity and trustworthiness.

Some guests on the account decided to display a written message or motto, while others illustrated a situation by citing details. For instance, a photo of hands with a cuddly toy in what appears to be a hospital bed provided a visual update on a life story. In other cases, the visuals supported the message of “living a normal life”, such as by showing outdoor activities, spending time with friends, acting in professional settings, or working out at the gym. When discussing difficult moments related to their illness, stays at the hospital, etc., participants often posted photos of themselves lying down, or displayed more of their body.

The pictures were occasionally edited graphically, or converted to black and white, but they predominantly follow the genre of snapshots. In most cases, they were not of professional quality and did not pretend to be; they were framed as instant shots that revealed details from everyday life. Their alleged spontaneity lends authenticity, as a photo taken at a specific moment with a phone camera reinforces the perspective of the author's post. This, in turn, contributes to creating a feeling of presence for the reader.

We also detected several occurrences of screenshots. One participant posted his portrait on a television screen when he was interviewed on national television news, another participant illustrated a post with a photo of a computer screen displaying pictures and headlines that referred to her in a national newspaper. These visuals contribute to framing the participant's self-representation through an external lens — in this case, through the lens of the media. This gaze or voice from a third party granted the participant a form of authority as a spokesperson.

Overall, we were able to recognize that varying usages of visuals enabled the guest bloggers to convey different types of emotion and atmosphere, sometimes using an external lens to create a

feeling of closeness, or the opposite to create distance. These strategies for managing distance to the audience illustrate a form of control over representations by selecting what can or cannot be seen, which focus is to be highlighted, and how personal one decides to be in the post. Digital closeness (or distance) places the author as a passive observer or an active character in relation to the story being told and this anchors the contact between the blogger and the audience to make it feel like a person-to-person talk.

The discursive and visual analysis of the material reveals not only a disparity of voices and experiences, but more importantly — and of particular interest to this study — various ways to relate to disabilities. We have identified four predominant narratives that were expressed in our data that challenge or reproduce contemporary discourses on disability.

5.1 Dealing with shame and guilt

Some of the female bloggers described the shame they experienced because their bodies did not correspond to the bodily norms they grew up with. Their shame sometimes assumed the form of self-loathing, resulting in self-destructive behavior such as eating disorders or self-harm. For instance, the blog posts recounted the difficulty in accepting one's own body while growing up, the experience of being ashamed of one's appearance. The message in these blog posts appeared to be that these women realized they had previously punished themselves for having a body that did not conform to the norm, something they could not change. They continued to compare their bodies to normative bodies their entire lives and felt shame for not living up to the expected norm. In their blog posts, they linked and articulated their own bodies in terms of body-normativity, thus making explicit the norm and making visible the social construction of what is perceived as a normal body and what is not.

Some writers also related previously having harbored guilt for not being grateful for all the treatments, surgeries, and rehabilitations they underwent, instead feeling relief when the treatments ended. Furthermore, some blog posts mentioned their previous feelings of guilt for not recovering from their impairment following the treatment. One of the aims of these posts appears to have been to question the wish to be cured, which is taken for granted solely to fulfill cultural expectations regarding how a body should appear. The connections of the signs and the articulations in these posts are made between the non-normative body on one hand, and on the other, they related aspects of their disabilities, such as the pain and physical problems that follow surgeries and prostheses, making explicit and challenging the social construction of treatment as the solution to disability. Another example is when one person wrote of feeling freedom when the last surgery ended and the doctors had finally decided that additional treatments would do more harm than good.

This narrative emerged from the life stories regarding one's own experience of living with disabilities, and consequently, it relates to not being ashamed, silent, or trying to conform. The confirmations from others in the comments frame the stories into a narrative that challenges the strong normative medical discourse concerning health, illness, and bodies, which people with disabilities encounter in contemporary Sweden.

5.2 It's not me, it's society

These narratives provide examples that describe the lack of access to public places and the limitations or exclusion this implies. For instance, one blogger mentioned that the only bathroom available was inaccessible, another observed that 'high curbs have prevented me from attending many

meetings'. Yet another example describes a child's difficulty in participating in a birthday party: 'Inaccessibility is not ok. Children with normative functionality can have friends who don't have normative functionality'.

In this narrative, society — or rather social structures and social planning that emanates from the normative views of body and normality (Campbell, 2009) — is an agent that is responsible for creating obstacles that exclude people with disabilities from accessing specific places and public spaces, as well as other arenas. The bloggers choose here to represent themselves as actors taking part in social activities and engaging with public spaces.

This first and foremost contains the social model of disability. This social model was developed in the mid-1980s to understand disability (Oliver, 1996). At that time, disability was rejected as a medical condition and the prevailing model was based on the assumption that society disables people. According to this conception of disability, it is not viewed as an individual body/mind trait, and this model changed the perception of disability from an individual limitation to limitations in social planning and structure. A distinction is thus made between impairment and disability. An impairment is said to be a long-term trait that affects a person's body or mind functionality, but what disables a person is the designing and planning of a society that meet the needs of the majority but neglects the needs of people who have impairments.

In these blog posts, disability was articulated in relation to inaccessibility. Claims were directed against society for not taking bodies with different functionalities into consideration. This is a step towards challenging ableist normativity, that is, that certain bodies and minds are the norm upon which every part of society is built (Campbell, 2009), in the sense that societal structures are criticized for not being created so that all bodies and minds can participate and not be excluded because of inaccessibility. Although no specific actor was explicitly mentioned, and agency was not clearly stated, the narrative expressed how society in general causes problems that affect people with disabilities because of the body-normative assumptions underlying social planning. In terms of self-representation, this narrative enables bloggers to position themselves as part of society, i.e. as social actors — despite being excluded from some public spaces, for instance — and not in relation to a medical discourse, i.e. not as patients.

5.3 I am like anyone else. I am normal

These bloggers made claims that they are similar to anyone without a disability. This was achieved by the articulations of the writer's usage of the pronoun "I" with expressions such as 'I am actually like anyone else', 'I live a normal life—whatever normal means', 'I live like any other 30-year-old', 'I do not suffer from my disability, I live with my disability. Otherwise, I am first and foremost a happy and positive girl with human worries and feelings'. They offer examples that one can have a job, travel, go out, etc., despite physical disabilities.

This narrative can be interpreted as challenging normative views on what it means to be "normal" by including all bodies and minds in the concept of normality. It thus functions as a type of claim to broaden the normative "normal", while continuing to reproduce normativity in the notion of normal, for example, by claiming that people with disabilities follow a normative life-path and work, make friends, fall in love and so on. Thus, the narrative does not challenge the body and life course normativity discourse by questioning the notion of "normal", or by shedding light on the ableist norm as a social construction and not given by nature.

According to Kafer (2013) and Campbell (2009), ableism has contributed to a critical explanation of the meaning of disability in society. From this perspective, society, social structuring, and social planning are based on an assumption that human bodies and minds are supposed to look a certain way and function in a certain manner. This mainly originated from industrialization and the concept of a norm that arose in the growing field of statistics (Davies, 2006). People with other functionalities are consequently excluded from access to and participation in society. This ableist normativity does not only concern people with disabilities, but also older people and those of different heights and weights than the norm. It is therefore ableism, and not dis-ableism, that calls for critical attention.

5.4 I have a diagnosis. I am not my diagnosis

These guest bloggers often commented on instances and situations in their lives when they have faced discrimination or a lack of understanding and knowledge regarding what a disability is to them. One person related that one's impairment is taken as the only explanation for all types of health-related issues, even those that cannot possibly be linked to the disability, thus making it difficult to receive or even ask for adequate help. Several bloggers provided examples of how they encountered prejudice because they were perceived as disabled persons rather than as individuals. Someone wrote about being talked to and treated like a baby during childhood because many people associated her/his physical impairment with a cognitive disability, or possibly due to the cultural metaphor of a disabled person being an "eternal child" (Kafer, 2013).

Some writers challenged the ableist norm in a few blog posts. These posts conveyed the normative ways of expressing what it means to have a disability through the use of rhetorical questions or simply question marks, thereby challenging and making explicit the social construction of these utterances. 'Do you take any medicine? Medicine for what? To be cured? Cured from what? My diagnoses are not illnesses'. Another way of challenging the ableist norm was to make the norm evident through a cultural construction. As an example, one blogger, mentioned previously having focused on conforming to the norm, and then realizing that it is not the diagnosis that is negative, but the norm surrounding it, what s/he calls 'the prejudices'. Yet another means of clarifying the ableist norm and making it visible was when one writer related: 'If we hadn't had a certain norm regarding what a body should look like, I would not have had to make such an effort to make my body conform to the norm'.

The bloggers did not explicitly claim that they understood their disabilities as a positive identity, but their narratives also argued for the recognition of their individual identities. This is in contrast to focusing on a collective patient-identity and/or diagnosis.

This narrative challenges the medical model of disability that portrays disability as an illness that must be cured/treated, which aims to correct and cure all bodies and minds that deviate from the ableist norm. Ever since the emergence of biomedicine, the hegemonic view of disability has been predominately biomedical. Thus, the normative understanding of disability that prevails has been to view disability in terms of sickness, diagnosis, treatment and cure. According to this medical model, impairments are perceived as losses and limitations that cause disability (Oliver, 1996). The disability, from this perspective, is expected to reduce a person's quality of life, and medical intervention is perceived as a necessity in order to cure or correct the disabled person's body and restore the disabled person to normality.

These four narratives reveal that self-representations in the Instagram campaign are related to various discourses of disability, and that the representations either adhere to dominant discourses or challenge them. In the next step, we discuss the conclusions that can be drawn from the outreach potential of this selected campaign.

6 Inreach and outreach communication

A fruitful line of inquiry has been to discuss communication in terms of inreach and outreach practices by approaching the various layers of communication, not least for minority contexts (Landzelius, 2006; Lindgren & Cocq, 2017). While inreach communication practices concern sharing and community building within a group, outreach communication relates to connecting with other groups and individuals to establish new networks, to inform, and to fill knowledge gaps, etc. Layers of inreach and outreach communication can often co-exist and we can assume that this is almost always the case online.

The guest bloggers participating in the Instagram campaign were aware that they were part of a campaign that aimed to raise awareness among non-disabled people about prejudiced thinking and behavior. The selection of bloggers was based on the life stories that they wanted to tell and that the campaign organizers found particularly interesting. Each participant was free to post pictures and texts as he/she wished, with no involvement from the campaign organizers.⁶ The bloggers participated by writing personal stories on how they are treated by non-disabled people, or how they perceive their disability and their experience of living a life with a disability in today's society.

The campaign made activist claims, and the intent was to raise awareness among the non-disabled. Nonetheless, the voices and the interactions on the account indicate that people with disabilities themselves were also a major group addressed. As evidence of this, several guests ended their posts with a message to other people in similar situations, such as “Stand firm and don’t let anything stop you”, or “to be different is never wrong”.

The actual reception and consumption (who sees and reads the posts) of the campaign is beyond the scope of our study. However, one of the basic affordances of Instagram is that posts and pictures generate reactions and this is achieved through threaded conversations (Sépulchre, 2018), “likes”, and emojis. Most posts stood on their own, and did not generate a threaded conversation. The degree of interactivity was often rather low, consisting mostly of “likes” and emojis. When the bloggers discussed, they often added comments, stories and experiences similar to the ones described in the posts. In a few instances, the discussions reflected different perceptions. For example, one person wrote that a diagnosis becomes part of one's personality, and that this person would not want to be without the diagnosis, whereas other users commented that they did not feel the same.

There can obviously be several explanations for the low degree of interactivity. Firstly, the phenomenon of filter bubbles has received considerable attention in Internet research over the last decade (Pariser, 2011; Pentina & Monideepa, 2014; Sunstein, 2009). The concept is used to describe the alleged secluded and isolated digital spaces in our online lives that result from content selection made by algorithms that are based on our online personal search practices and preferences (Pariser, 2011). The feared consequences of these types of spaces are the cultural, political, and intellectual isolation they might result in, and that we as internet users are becoming increasingly separated from information and opinions that deviate from our cultural, political, and intellectual preferences and habits. In the case of the campaign in our study, we can assume that it is difficult for Instagram users

with limited knowledge and/or interest in issues related to disability to find or receive information on this type of campaign.

In our material, we noticed that the posts on Instagram, although they initially addressed people ‘with a normative functionality’, received interactions mainly from accounts used by people with disabilities (based on what can be found on the account profiles). This can be interpreted as if most of the bloggers were writing to a community of other disabled persons, and the comments were also from other persons with disabilities. Although the target group mentioned in the campaign outline was not the primary group that interacted with the guest bloggers and the other related accounts, the campaign appears to have filled an important function. It created a public support space for sharing stories and experiences, a space filled in by people with disabilities who received support and together built a community around a shared similar interest by questioning stereotypes, prejudices, norms and discourses regarding what it is like to live with a disability.

Filter bubbles are often described as restrictive and excluding in terms of access to information. They can, nevertheless, have positive effects in some cases (O’Hara, 2014; Weinberger, 2008). In our study, the inreach dimension of the campaign, that is, the communication within a community of activist bloggers with disabilities, appears to be primary. The beneficial effects of such a dimension for community-building and support should not be underestimated. Several guest bloggers ended their week on the rotating account with a message expressing their gratefulness for the support and encouragement that they received. Some also summarized by commenting that they received useful advice on how to deal with specific difficulties as well as their rights. Some of the posts also underscored the importance of knowing that ‘we are not alone’, and of meeting people in similar situations. From this perspective, the inreach range of the campaign grew stronger than it was initially intended, at least as it was expressed in the objectives of the campaign that was introduced in the account profile.

A second approach to this low degree of interactivity is to interpret the space created through the Instagram account as a space for dialogue for people with disabilities. People with a normative functionality who are addressed in the campaign description were explicitly requested to ‘Take a step back and listen’. Interactions and dialogues were therefore clearly discouraged. The description created a form of separatism where people without disabilities were included as a passive audience (Hagren Idevall, 2015). From this perspective, the Instagram account was not intended as an isolated space; people without disabilities and with a lack of knowledge regarding what it is like to live with a disability, were included in the audience, but as passive listeners. The only instance where this group was directly addressed was in the account description quoted above. This type of online separatism creates a space where people can talk, take action, and conduct activism based on their perspectives without having to explain, represent, or educate others (Collins, 1990; Hagren Idevall, 2015). We can assume that outsiders restrained themselves before writing a comment, as they were explicitly asked to ‘step back and listen’. However, it is not possible for us, nor is it within the scope of this study, to evaluate if and how this specific space might function in terms of separatism. We do know, for instance, that comments were moderated, and in some cases deleted⁷; consequently, we can also ascertain whether there was more interaction that occurred during the campaign than what is accessible on Instagram.

7 Conclusions

The guest bloggers wrote about their experiences of discrimination or their daily life living with a certain type of disability and they did this from different viewpoints or within different discourses. The empirical data contained a diverse set of claims, all with the common goal of acknowledging and making discrimination visible and bringing about change. The life stories, not surprisingly, varied to a great extent. The narratives that were identified indicated a variety of strategies for understanding disability, but also, more importantly, that people relate to established discourses about disabilities in various ways. Contrary to the assumption that is dominant in the medical model, it became evident that the meaning of disability is not as unequivocal. Multiple and overlapping understandings of disability also coexist when people with disabilities themselves discuss disability.

The limitations of this study imply that additional research needs to be conducted on self-representations of people with disabilities on social media. Instagram is but one of many social media platforms and the various social media services differ in their affordances and their implications for self-representations and for their potential to reach out. There is a need for platforms and public spaces where people with their own experiences of disability can describe their situation in their own words and not be described by non-disabled people, which continues to be the most common practice. This is especially important for representations of all other aspects of living with a disability than the medical diagnosis, which is the main representation of disability in any media. In order to raise awareness among non-disabled people of discrimination, campaigns of this type are needed to depict people with disabilities as social and political subjects, not solely as those having a medical diagnosis.

As we demonstrated in this analysis, one difficulty with this type of campaign might be the outreach potential of social media. Although our study does not allow us to draw conclusions on the impact of these voices in terms of change or public debate, we can, however, conclude with remarks regarding the potential of social media and social media campaigns for marginalized communities. Even if the outreach potential might be modest, the inreach potential of the campaign and the role of such digital practices for the community itself is highly important. As several bloggers expressed, their participation in the campaign contributed to finding and providing support as well as to a form of community building. With this campaign, the bloggers also took the stage by requesting that the audience listen. They communicated that it was their turn to do the talking, that as people with disabilities, they need to be the ones talking about themselves, rather than having others talk about them.

This campaign is also an illustrative example of personal stories contributing to the politicization of disability as a subject position (Pearson & Trevisan, 2015). As mentioned earlier, and in line with Kafer (2013), people with disabilities have limited opportunities and places to participate in public debates and to contribute to social change. There is also a widespread perception that disability, especially from the medical understanding, is a natural fact beyond any political consideration. This removes disability from debates concerning prejudice, cultural bias, and rights. The campaign examined in this study can be viewed as an effort and a step towards an increasing visibility and politicization of disability and a political framing that is indispensable for social change.

Disclosure of interest

The authors declare that they have no competing interest.

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Endnotes

¹A rotating account implies that different persons assume responsibility for sharing posts and pictures, often a new person every week. The account is curated in the sense that it gathers and presents content that pertains to a specific topic.

²Interview, October 9, 2017.

³Our translation from Swedish "normfungerande".

⁴Interview, October 9, 2017.

⁵For ethical reasons, we have decided in some cases not to quote the guest bloggers, for instance in order to avoid revealing information such as names, places or other identifiable details. This example is a fabricated post (Markham, 2012) based on data included in our material.

⁶Interview October 9, 2017.

⁷Interview October 9, 2017.