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Social media and disability advocacy organizations: caught between hopes and realities

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\textbf{ABSTRACT}

This article examines the role of advocacy organizations and their use of social media within the field of disability in Sweden. How do the organizations negotiate digital media, and what are the (intentional or unintentional) consequences related to the use of social media? With focus on the representatives of advocacy organizations, we study how they reflect and act in order to balance various motives, and what challenges and ambiguities that arise. On one hand, there is a perceived need to be online and communicate with members and the surrounding society. On the other hand, digital communication induces a divide between those who have the resources to take part in such communication, and those who do not – in terms of digital competence, economy, age, cognitive abilities, technical equipment and digital connection. The heterogeneity of resources and target groups inevitably challenges both the ideals of inclusion and intentions of advocacy organizations.

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social movement; mediatization; power negotiation; advocacy; digital divide

Points of interest

- Today both individual persons and different organizations use social media (Facebook, Instagram, Twitter and similar) to talk to each other, to find friends, to give and seek information about different things and possibly to gain support for their cause in public.
- Also advocacy organizations use social media to inform and support their members, to speak on behalf of their members and to society.
- This article studies how different disability advocacy organizations reflect upon the use of social media in their work – how they use it, why, and for who.

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This is an Open Access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.
This study shows how difficult it is to take the interest of different target groups into consideration – for example people with various disabilities, of different age and economic status, their families, and the wider society – and to still address and include everyone.

Particularly young people, but also others, might not need advocacy organizations, they have social media.

Introduction and aim

The Internet nowadays tends to permeate almost every aspect of life. In many ways, the Internet – in combination with technical developments and devices such as computers, smartphones and tablets, as well as software to access the Internet – has changed the ways in which people with (or without) disabilities access information, communicate with each other and build communities. In this time of changing patterns for communication, we see how individuals, news agencies, political parties, civil authorities, etc, seek to navigate this field. New and potential forms of communities and power are negotiated in and through digital media – but still in relation to offline structures (cf. Allan 2009; Howard et al. 2011; Lindgren and Cocq 2017; Rainie and Wellman 2012; Turkle 2011). There is consensus that such developments will have a long-term impact on our society, but the full consequences are yet to be seen. So far, the vast majority of research on disability and online media has focused on access and accessibility (Ellis and Kent 2011; Trevisan 2014). These concerns indeed remain relevant today considering that people with disabilities use the Internet and social media less than people in general (Borgström, Daneback, and Molin 2019; Chadwick and Fullwood 2018; Scholz, Yalcin, and Priestley 2017). This inequality corroborates the idea of a digital divide, which continues to be a popular theme among internet researchers (Trevisan 2014; Dobransky and Hargittai 2006, 2016).

The present study offers insights into the social media use of disability advocacy organizations in Sweden. Given the vital role that these organizations play, and their growing reliance on social media for their efforts (Andrews and Edwards 2004; Obar, Zube, and Lampe 2012), it is important to gain a better understanding of the effects that governance provided by social media services can have in relation to the different aims and objectives of these organizations (see also Hestres 2017). To an increasing degree, today we can see how advocacy organizations also within the disability field use various forms of social media, for example, Facebook, Instagram, Twitter, YouTube and Snapchat, in order to stay relevant in an increasingly media-saturated society, to promote the organizations among current members and recruit new members, to build a sense of shared community and to take part in the public debate on issues concerning their members.
Communication is understood to be key to contemporary interest-driven organizations.

This article aims to understand and analyze the role of advocacy organizations within the field of disability in a society that is becoming increasingly digitized, and where the authority of traditional institutions (such as the advocacy organizations) is being negotiated. Traditional advocacy organizations are often structured hierarchically, established decades ago, pre-dating the Internet. Thereby the article consciously omits more recent, internet-based, initiatives and rather specifically highlights the tensions these traditional organizations experience when they engage with digital media.

The article is based upon interviews with twelve representatives from the main advocacy organizations representing people with a broad range of disabilities in Sweden. Focus is on how they reflect and reason about the new situation and the consequences social media brings to the traditional organizations.

A point of departure is to analyze how these advocacy organizations act to balance different motives for social media activities and what challenges and ambiguities arise when these activities need to respond to different demands and expectations. The research question is what ambitions and activities are perceived as necessary in order to respond to different expectations and purposes, e.g. recruiting new members, providing information, giving voice and debating issues important to their members, raising societal awareness on issues related to disability etc. In other words, what is the role of advocacy organizations in an increasingly digitized society, and what are the special needs and consequences to consider in relation to disabilities? This overall research question can be divided into the following sub-questions:

- How do representatives within the organizations negotiate digital media?
- How do the representatives negotiate between the expectations articulated in relation to these media and their application?
- What consequences are seen and can be foreseen within these organizations in the wake of an increasing use of digital media?
- Are there processes of unintentional exclusion of some groups articulated in relation to contemporary digitization?

This article is concerned with research on social media and advocacy organizations in the field of disability in Sweden. It is thus not concerned with the social media-related experiences and practices of disabled people themselves – which would be an important contribution to the understanding of the complex role of digital media in the field of disabilities, but it is
outside the scope of this article. By analyzing the relationship between social media activities, and the work and ambitions among advocacy organizations for people with disabilities, this article contributes to an enhanced understanding of the use of social media by these organizations as well as their ambiguity toward it. As becomes clear in this article, there are some apparent paradoxes in the way representatives from the different advocacy organizations deal with these matters.

**Background and context**

Social media, represented by global media companies such as Facebook, Instagram, Snapchat and YouTube, have over the last decade grown in importance and magnitude in the lives of many people for finding information, amusement and community. About 2 billion people use social media worldwide, and, for example, Facebook had as of late 2018 2.2 billion monthly users all over the world, YouTube about 1.9 billion users and Instagram about 1 billion users (https://www.statista.com/statistics/272014/global-social-networks-ranked-by-number-of-users/). Social media is said to have an impact both in our individual lives and in large-scale political processes. It affects our views on self-identity and representation, and through a variety of channels we build our personal ‘brand’ in the public, and we (potentially) connect in new forms over traditional boundaries. New interest-based groups are formulated to share experiences, strengthen identity and take action (cf. Castells 2000; Rainie and Wellman 2012). Broad-scale social mobilization is allegedly possible through the use of social media, and well-known examples can be found in the upheavals of the Arab Spring or the election of the US president in 2016 (cf. Howard et al. 2011; Khondker 2011; Kreiss and McGregor 2018). Media scholars such as Hjarvard (2013) and Lundby (2014) claim that in contemporary (Scandinavian) society anyone who has a message to communicate needs to comply with the logics of media, and they use the term ‘mediatization’ to describe this process. We see it in, for example, politics, within religion and in businesses. The message needs to be ‘packaged’ in media-friendly portions and distributed in and through (increasingly digital) media channels to the public.

With the Internet, novel modes of networking (Ineland, Gelfgren, and Cocq 2019), of community building (Molin, Sorbring, and Löfgren-Mårtenson 2015), for socializing (Löfgren-Mårtensson 2008), self-representations (Cocq and Ljuslinder 2020) or for increased visibility (Pearson and Trevisan 2015) have emerged, providing people with disabilities with new tools for presence, communication and empowerment. In the wake of the process of society’s digitization, there is an increasing gap between those
who are ‘in’ and those who are not – those with a high level of digital literacy and those without, those who have infrastructural access and those who lack it, and those for whom the technology is accessible and those who are excluded by the technology. There is a growing divide between the alleged ‘digital natives’ and those who are ‘digital immigrants’ and those who are left outside (even though these concepts are debated) (cf. Palfrey and Gasser 2008). Factors such as economic resources, age, class, geographical location and different forms of functional or cognitive abilities contribute to this divide. At the same time, there has also been a tendency among internet scholars to assimilate accessibility issues to the digital divide paradigm (cf. Vicente and Lopez 2010), which points to inequalities caused by a gap in internet access and use and argues that online media might be threatening for democracy and society more generally (Norris 2001).

Over the last decade, much has been written about the impact of a digital divide on the lives of disabled people, centered largely on issues around accessibility and social inclusion (cf. Ellis and Kent 2011). As such, these issues arguably resonate with key arguments in both disability and internet studies.

Given this propensity, this article touches on the way these new opportunities have given structure to and provided online strategies for disability advocacy groups to have an impact on both a political and societal level. As Chadwick (2013) argued, politics are usually defined by organizations, groups and individuals who manage to blend older and newer forms of media. For instance, social media – and social media platforms – have become increasingly integral to contemporary forms of activism and campaigning and are used, among others, by social movements and advocacy groups. Despite an increased awareness of the Internet’s ambivalence for people with disabilities, research also indicates that it has the potential to promote civic participation among people with disabilities and to strengthen the influence of disability organizations in policymaking (Pearson and Trevisan 2015). However, advocacy organizations – in this study more specifically organizations in the field of disability – are in the midst of this process. We see how they are drawn in different directions in seeking their role in a mediatized society and taking part in the public debate; they are rather traditional institutionalized organizations representing their members (often with a shortage of various resources), while at the same time they are aiming to prove themselves still modern and relevant in a digitized society and thus attractive to new members. Studying the role of advocacy organizations in contemporary digitized society highlights both the anticipated potential and the actual dilemmas for the organizations themselves as well as for the individuals they claim to represent.
Disability advocacy organizations and social media

The welfare-state policies in Sweden, with its ideals of equality for all citizens, have resulted in a large number of well-organized disability groups and associations. However, the advocacy for giving people with disabilities the same rights – and responsibilities – as everyone else was originally formulated in 1969 by Bengt Nirje of the Swedish Association for Retarded Children as a ‘normalization principle’ (Nirje 1969, 181). Today, notions of normality – and ideas of normal lives – constitute a core policy in the field of disabilities in Sweden.

There is a wide variety of user organizations, from small informal grassroots organizations focused on peer support, to larger service user-run organizations with paid staff, to national-level umbrella organizations (Näslund, Markström, and Sjöström 2018; Baumann 2014). Besides governmental efforts to create user involvement in the welfare system, service users have a history of organizing themselves collectively and independently of the state (Barnes 2007). What Näslund et al. (2018) refer to as the ‘service user movement’ might be understood as a social movement where users of various public services organize (predominantly through ‘user organizations’) with the aim to improve their situation. According to Persson Bergvall, and Sjöberg (2012), the disability movement, which began to take shape in the 1860s, is an early example of such a social movement. About a century later social mobilization among people with disabilities grew, laying the foundation for the modern Swedish service user movement (Markström and Karlsson 2013). An important struggle for the Swedish disability movement has been to change the perspective on disability policy from being primarily a matter of providing care to one of citizenship and human rights (Hugemark and Roman 2007). Today social media allows advocacy organizations to raise awareness about disabilities and to stimulate public communication and interaction. It also allows organizations to connect to members and citizens. However, as pointed out by Bail (2016), one factor that might determine whether advocacy organizations stimulate large social media conversations is how the contents of their posts and messages fit into the preexisting discourse about an advocacy issue (e.g. living with disabilities).

In Sweden, two umbrella federations cover most of the disability organizations. Most prominent of all is the highly influential Swedish Disability Rights Federation (Funktionsrätt Sverige), which acts as a referral body in relation to the government, the parliament and the national authorities. The federation was founded 1942 and consists today of 41 national disability organizations with about 400,000 individual members. Equally Unique (Lika Unika) is a Swedish human rights federation focusing on the rights of persons with disabilities according to the UN Convention on the Rights of Persons with Disabilities (CRPD), and the UN Convention on the Rights of the Child and
the Convention on the Elimination of All Forms of Discrimination against Women. Equally Unique was formed in 2009 and has six national associations and represent about 80,000 members. Among the informants in the present study, three were part of Equally Unique and two were part of the Swedish Disability Rights Federation, while two advocacy organizations were independent and not part of either umbrella organization.

Advocacy work is commonly viewed as an eminent feature of nonprofit organizations’ activities in general, allowing them to engage and represent their constituencies. Such work might include giving voice to diverse views and demands, promoting social and/or economic justice, contributing to a more active civil society and strengthening democracy and equality of opportunity (cf. Almog-Bar and Schmid 2014). Social media is often believed to offer advocacy organizations the potential to stimulate conversations that spread rapidly across diverse groups of people (Bail 2016; Bakshy, Messing, and Adamic 2015). On the other hand, as pointed out by Bail (2016), advocacy organizations do not always produce messages that inspire far-ranging conversations among social media users, and a majority of organizations receive little or no attention. Nevertheless, public conversations usually spread awareness about advocacy issues that are perceived as important by the constituencies, and social media communication is often described as the soul of democracy (Shah 2016). These organizations are, as we will see, caught in between the traditional format and a newer (mediatized) format – a situation that will be studied and discussed here.

Method
Informants and data collection
The present study is based on a qualitative data set resulting from 12 semi-structured interviews with representatives from seven different advocacy organizations in Sweden. The interviews were conducted between January and April 2018. Although there are far more advocacy organizations in Sweden, we selected the large and well-established advocacy organizations in terms of numbers of members and that represent people with different types of disabilities (e.g. people with intellectual disabilities, vision and hearing impairments, neuropsychiatric disorders, etc.). These organizations were established before the emergence of the Internet, and thereby specifically affected by the implementation of digital media in their everyday work. Within these organizations, we identified and selected informants actively working with the organizations’ internet and online activities. Hence, informants were chosen based on the key roles they play in planning and executing digital advocacy strategies. It should be noted that we decided to interview representatives of the national associations in these different
disability organizations, which means that their somewhat autonomous local member organizations were not included in the study. Although we could have included more organizations, we believe that our selection criteria were legitimate in order to be able to draw conclusions on social media strategies and that our analysis is representative of Swedish advocacy organizations. Although the organizations’ advocacy areas may overlap, there is also a range of diversity in their characteristics such as disabilities and number of members, areas of interest, aims and ambitions, and, as shown in the article, their primary vision for engaging in online activities.

For the aim of this study, we constructed an interview guide comprised of a number of open-ended questions about the advocacy organizations’ use of social media, e.g. how to inform and communicate with members, their attitudes toward social media (for instance as inclusive or exclusive for people with disabilities), their positive and negative experiences of social media activities, who decides on social media strategies, if and how adjustments for members (with different forms of disabilities) are made, if and how the Internet and social media are empowering to people with disabilities, etc.

The length of the interviews normally ranged between 45 and 60 min. Taking the geographical distribution of informants into account, dispersed over the country, we decided that the interviews should be done over the telephone. Telephone interviews are often depicted as a less attractive alternative compared to face-to-face interviewing (Novick 2008), but telephone interviews have both strengths and limitations. The absence of visual cues via telephone may result in loss of nonverbal data such as body language, which could reduce the researcher’s ability to interpret responses and thus address follow-up questions. On the other hand, telephone interviews may allow informants to feel relaxed and able to disclose sensitive information, and such interviews are also cost effective and time efficient (Block and Erskine 2012). The possibility to conduct telephone interviews for the purpose of this study was assessed beforehand to see if our method had to be adjusted to the specific context of the interviews (Farmer and Macleod 2011), but in only one case the interview-situation had to be adapted and a sign-language interpreter was involved.

Method of analysis

To analyze advocacy organizations’ use of social media and the Internet, we used the method of content analysis to describe and compare the data collected through the interviews. A theoretical approach to thematic analysis was taken (cf. Braun and Clarke 2006) whereby coding was specifically related to the use and experience of the Internet and social media activities. Themes were identified to capture important patterns across and within the
interviews. The methods used to analyze our data fall especially into descriptive techniques, and our approach took inspiration from Braun and Clark’s (2006) steps for analysis.

First, we used a qualitative approach to explore and categorize the semantic content in the transcribed interviews. We read through and coded the data guided by the research questions and broad analytical questions: how do the advocacy organizations describe their role in an increasingly digitalized society? What is their purpose for using the Internet and social media? What benefits and challenges with online activities have they experienced? Synonyms and different grammar forms – e.g. definitive/indefinite form, singular/plural – were considered semantically equivalent and thus put into the same codes. During this step, we also developed tentative categories. It would have been possible to generate more categories, but the chosen level of abstraction was useful in that it enabled the identification of what clearly reflects the experiences and strategies of disability organizations when it comes to social media activities. The categories that emerged through this topical reading rapidly indicated a set of dichotomies and paradoxes, for instance, about age groups, the necessity and limits of social media, etc. In our analysis, we chose to focus on these paradoxical relations as a point of departure for identifying the prerequisites, dilemmas and strategies that the advocacy organizations must deal with when being active on social media in contemporary society.

Ethical considerations

The research complies with the ethical principles of research in the humanities and social sciences according to the codex of the Swedish Research Council (Codex 2011). The authors paid particular attention to possible implications for people with disabilities in the presentation and analysis on the interview data, in regard both to specific details (to ensure confidentiality) and to the wording (to avoid general or unnuanced descriptions). The authors took appropriate steps with regard to access, informed consent and confidentiality. Information regarding the aim and objectives of the project, the ethical guidelines and the methods were provided to the interviewees both orally and in written form. Ethical approval to conduct this study was obtained from the Regional Ethics Board in Umeå, Sweden (2017/218-31).

The paradoxes – on how to be an advocacy organization in a mediatized society

The twelve informants, all representatives for the different advocacy organizations, followed approximately the same narrative when it comes to their views on the use of social media within the advocacy organization, how their
work is related to the members of the organizations and other target groups, how they see social media in relation to contemporary society and how they view the potentials and the pitfalls of social media. They are all well aware of the different needs in relation to the various disability groups they represent and all of them are consistent in expressing rather ambiguous viewpoints on the use of social media. We focus on disability advocacy organizations through the strategists responsible for planning, managing and coordinating interactions between the organization, its members and other external stakeholders via the Internet and social media. In order to highlight the tensions, a contemporary digitized society entail for the advocacy organizations, this article focuses on three intertwined paradoxes and ambiguities.

- Being relevant – Negotiating online activities
- Democratization – Inclusion and exclusion
- Ambiguity – Balancing potentials and difficulties

**Being relevant – negotiating online activities**

Online activities are motivated by the need for visibility and the risk of not being visible or outside parts of society if the organization chooses not to have a presence on social media. It is also related to the idea that everybody is online nowadays, and in order to keep up with the surrounding society, the advocacy organization needs to be present and active online too – that is where the people are and where the action takes place. “We simply have to be there if we want to be visible, so that we don’t disappear” (Interview 1), as one of the representatives expresses it. This is corroborated by another interviewee who tells us that “if we wouldn’t use social media, we would preclude ourselves from an important part of society” (Interview 2).

The speed for sharing information is yet another reason. Despite the many positive implications of social media strategies brought forward by the informants, the members, i.e. those for which the organizations advocated for – people with different disabilities – created a tension between online and offline communications strategies. The following quote highlights this tension:

Through Facebook and Instagram we reach members, through Twitter we reach politicians and policy makers… In addition, we also distribute a monthly newsletter, and there are still more members who follow us on Facebook… we also send our members our magazine 4–5 times a year, and in the magazine we always have a number of pages of information about what is going on in the organization. (Interview 5)

Informants recurrently express a frustration and are torn between the possibilities digital media promises and the fact that their targeted group lacks the resources to use and exploit these possibilities. Often there seems to be
a vague sense of the promises digital media gives and how to actually and practically convert and implement these promises into real action. Although the advocacy organizations have developed a social media presence, to which they seem to have become increasingly accustomed, they appear to have little choice but to also maintain traditional media channels (email, member magazines, weekly newsletters etc.) given that not all members are active on social media. At times, this seems to put the organizations and the informants in an awkward position of making use of two sets of media strategies – i.e. one-way information versus mutual communication. The somewhat paradoxical relation between going online and remaining offline as previously, is apparent:

Quite many don’t have computers. And when they have one, it is an old one, or with a really slow internet connection. ... Many of our members are also poor, they can’t afford the technology required, they don’t have smartphones and well-functioning computers… and if they have a computer sometimes they have not learned how to use it. (Interview 1)

Many people with intellectual disabilities don’t have access to the Internet. It is a big problem. (Interview 2)

Here, the interviewee underscores that access to computer and to an internet connection among their members cannot be taken for granted. Our data also indicate that a growing generational gap between older and younger members may increase this propensity:

A rather big group is the elders, the older generation. And some of them don’t have a computer, don’t use email, and don’t have Internet. (Interview 11)

The tension here is the fact that many of the members the organizations represent do not use or have access to social media. The excluded groups identified in the interviews are the elderly, people with low or no incomes and who lack the financial possibility to have a computer or other device, and those who are excluded due to cognitive disabilities. There is a clear tension between what the organization (or rather the interviewed representatives) wants to do (reach everyone, be involved in a dialogue, recruit, be visible, be inclusive etc) and what can be done due to the difficulties in reaching people. Part of the problem with feasibility is the target group(s).

The organizations want to reach several target groups – including different generations, people with disabilities (sometimes different types of disabilities) and their parents and relatives – and these target groups have different degrees of digital literacy, computer skills and physical and cognitive conditions. Given the strategic position of our informants, it is evident in our data that they face a delicate balancing act in their online strategies:

It is my experience that many people have difficulties catching up, which means that I have to be very pedagogical in explaining things. I’m struggling with that –
how to describe all this [social media] with enthusiasm but without taking over, you understand? Guiding people and making them understand the value of social media and being digital... without scaring them. Lots of people get scared; we have many older members and they tend to be either provoked or scared and feel that this is nothing for them. (Interview 5)

There is, in other words, an experienced need to be online, but the informants struggle to make the best out of their online activities. On the one hand they see the relevance and the advantages in being online, but on the other hand the people on the receiving side do not always have resources and access to respond to their online activities.

**Democratization – inclusion and exclusion**

In relation to aspects discussed in the interviews is the potential power of participation and influence, as well as efforts toward democratization. On one hand, social media is recognized for having the potential to increase the possibility of participation in decision-making, debates, events etc, and thereby to contribute to a process of increased democratization and user involvement. The interviewees talked about the democratization aspect as having influence and having a ‘voice’ – such as, ‘Everyone can create themselves a platform if they want, and they can make their voice heard’ (Interview 2) – but also as an almost paradigmatic shift in how the organization ought to communicate with its members: ‘It is a question of democracy, which we have moved from information to communication’ (Interview 3). In a more detailed account, these democratic and inclusive potentials were apparent:

For me, democracy is about giving people a voice, especially people traditionally without a voice, for instance, our members. (Interview 3)

The aspect of democracy is about more people knowing their rights and having abilities to make their voices heard ... many of our members (the disabled) have experiences of not being listened to. (Interview 10)

On the other hand, the limitation for reaching out to members implies that this inclusive potential is ineffectual. The democratization aspect clearly appears as a utopian idea, obstructed by the hindrance of possibilities, not least because many of the members do not have access to a computer or internet connection.

Taken together, I think going digital gives us a new platform where we can take a democratic approach. (Interview 3)

When discussing the dynamics of inclusion and exclusion, the informants agree that the Internet is not inclusive by default for people with disabilities, but some groups have more or fewer disadvantages than others online.
I think it [the Internet] can give a lot of possibilities, not least for those who are younger today, when they use different forums on social media and have their [own] tablet. … But for older people who might not have any experience at all, there has to be someone who can help. (Interview 7)

Age is mentioned in many of the interviews, but principally as a generational aspect, for instance, ‘the mums’, i.e. the parents in relation to the children, or ‘old ladies’ and youth. At the same time, age is not only a matter of being a digital pundit, and it is also a matter of what one expects from advocacy organizations. The institutional form of these organizations is seen as a reminiscence from an almost outdated society where democracy was learned and executed in and through advocacy organizations, political parties, unions and other formalized associations (compare with, for example, Putnam 2000). Today the structure of traditional organizations is experiencing a decline in interest overall – which the representatives acknowledge and point out as problematic for them. One expresses it as:

The young members [of our organization] are not interested in being part of an organization such as our association today because they don't have the time to invest, be on the board, etc. This form of organization that we have in Sweden, it starts to feel old-fashioned and does not appeal to the younger generation. (Interview 12)

Here the Internet fosters a new way of organizing for participation. Young people have, to a greater degree than older people, the possibility to access (digital) arenas for participation and to be part of an inclusive community. However, this happens outside the established structures the advocacy organizations represent and provide. If engaging in specific issues, (young) members at times act outside organizational frames through social media and their own networks. These initiatives are perceived as more efficient for airing one’s voice compared to advocacy. As one informant says: ‘After all, we are an organization, and as such we have many things to take into consideration’ (Interview 8). At the same time, the advocacy organizations also want to include and ‘squeeze in’ the young and the digitally skilled through a format they are familiar with. Whether or not they succeed in these ambitions seems to be a matter of tone and appearance and of whether they are perceived as relevant to current and potential members:

I would like to see that we are more actively analyzing where to find potential new young members. Where are the young people we would like to see in our organization? Part of why we don’t reach them, I think, depends how we are perceived … it is about language, style, appearance, etc. In addition, young people don’t engage in unions and organizations in the way people did earlier. (Interview 6)
What comes out from the interviews is that the Internet may be inclusive in some cases, but this depends on various factors that do not primarily have to do with the technology or the disability in itself. One needs to be nuanced about high hopes regarding the Internet in relation to people with disabilities, and as one interviewee says:

One should not overestimate the importance of it [the Internet] then, it is not a revolution for people with disabilities, it is still the case that, as a group, they are in a subordinate position in so many different ways, and it also remains so with the Internet. (Interview 9)

The informants refer to structures in society, age and generation as the cause of limitations in many cases – rather than the technology itself or the disability. Consequently, on the one hand social media is a means for including people, building networks and airing previously unheard voices, but on the other hand the use of social media induces a rift between the digitally skilled and equipped and those who are not.

**Ambiguity – balancing potentials and difficulties**

Broadly speaking, informants see the potential in using social media for reaching out to their members and potential members and for being part of setting the agenda regarding their different areas of interest. They have seen a shift in communication over the years, and one informant expresses this as a shift from giving information to being involved in mutual communication. One informant even claims there is a ‘paradigmatic shift’ regarding the role of the advocacy organizations in relation to their members. However, they still express doubts about the possibilities for actually reaching out and communicating with the groups they represent – and this goes especially for the groups who have limited supportive, economic or cognitive resources.

One apparent area of ambiguity is associated with the informants’ official assignments. Our findings indicate that they are struggling with their assignments, asking themselves who they are working on behalf of, and if they should focus on internal communication or outreach. Instead of giving information to the members, as they are used to doing, they are now supposed to be involved in an act of mutual communication. Some emphasize the difficulties in keeping the organization together across age and abilities when digital literacy and availability tend to introduce a rift within the organization and between different groups of members. Many, if not all, informants touch on the need for being online, not the least to reach and communicate with the young generation already online. At the same time, they also express concerns that they (their organizations) face the risk of losing contact with the older generation, which is the backbone of the majority of organizations, if they go online. Some organizations also struggle with the extent to which
their efforts at engaging in activities or launching campaigns are perceived as relevant for (primarily young) members. The following quote is illustrative:

We have many committed, motivated, and competent members who speak their minds and want to raise their voices, and feel that we as an organization are too slow… then they create their own networks or blogs and find their own channels to engage in specific issues. (Interview 4)

Although this and similar remarks implicitly acknowledge people with disabilities as being more than passive information recipients, a recurrent theme is that age is used to describe the different conditions and interests for various groups. Even though two different groups are identified in the interviews (the older ones and the younger ones), it is interesting to note that these two groups are placed in relation to each other and compared, but that ‘younger’ and ‘older’ do not in fact include specific age groups. In some cases, the ‘older ones’ are the parents, in other cases ‘young people’ are youngsters, while in one case those who are up to 40 years old are mentioned as ‘the younger ones’. The ‘older ones’ can then be parents (to younger children), the elderly in general, or those over 80. The differences in conditions and interests are then based on the comparison and the dichotomy created rather than the different groups.

Another area of ambiguity in assessing potentials and difficulties is associated with the extent to which members are allowed to comment and provide feedback on various initiatives. Factors such as social effects of disabilities, a propensity for emotional behavior and lack of integrity, and members’ vulnerability in online environments are recurring reasons for this hesitation. Although a majority of the informants have a predominantly positive view of the potential of the Internet and social media, they see difficulties too: ‘It [social media] has given people totally new possibilities to engage and to find new contacts in a way that was not possible before’ (Interview 5) and, ‘It is a fantastic means to share knowledge, to actually bounce different ideas and take impressions from each other’ (Interview 7). They also have a more cautious attitude mentioning the flip side of social media, referring to threats, harassment, risk for misunderstandings, and even in one case examples of bullying campaigns (Interview 12). All informants state that people with disabilities are more exposed to risk. Although this is a widespread opinion, none present their own experiences of members being exposed. In addition, the reasons for why people with disabilities are considered more exposed to risk vary. Different disabilities might increase or decrease these risks, and these risks might also take different forms. This negative side of internet interaction is not considered to be as strong as the positive side, but on direct questioning the informants formulate their concerns. According to one informant:
Some really interesting statistics from the Swedish Media Council show some pretty serious numbers when it comes to bullying and disabilities, for example, that three times as many youth with disabilities, and then first and foremost girls, are exposed to violence and abuse online. Of course, that is a challenge and something we need to address. It is known that at least when it comes to neurodevelopmental disorders they are more exposed to violence and abuse, but when it comes to persons with cognitive disabilities there are no such surveys. (Interview 3)

The informants’ views on potential threats (and exposures) led them to actively safeguard their members’ integrity and security by ‘monitoring websites and comments’, ‘deleting posts written when frustrated’, ‘creating and administering closed groups’ (on Facebook), ‘producing and distributing information’ and ‘creating policy on how to behave on social media’.

All in all, the informants primarily see the positive aspects of the use of social media as a means for inclusion and participation, and they claim that social media can strengthen each individual as well as different individuals as a group. The value of online presence and member-driven campaigning and debate is obvious in our data, but so also is a hesitation to give influence to online active members and how to respond to the majority of (off-line) members (cf. Goggin and Noonan 2006; Trevisan 2014).

Discussion and implications

Asking how representatives conceptualize digital media, this study shows that advocacy organizations express a significant reliance on social media communication and activities and a sense of necessity of having an online presence, while at the same time they acknowledge the sometimes low online presence among their current and potential members. Also evident in our findings is a variety of reasons for online presence, such as staying relevant in a mediatized society and the possibility of informing and communicating with members.

In term of the consequences and implications of an increasing use of digital media, this study sheds new light on how the Internet in general and social media in particular can aid disability organizations in engaging in advocacy work and how social media is negotiated in relation to their members. It is believed that such a research approach, particularly with a focus on social media strategists in these organizations, goes some way in revealing the challenges and opportunities of managing social media (cf. Guo and Saxton 2018).

What is obvious, and at focus in this study, is the paradox between expectations and implementation of digital media, in this case in relation to the advocacy organizations. As shown in this study, the organizations have embraced the digital in an effort to reach out, include and give a voice to
their members. Digital media is often praised as means for mutual communication, participation, inclusion, and giving voice to the unheard voices, and here the advocacy organizations are expected to aid the people they represent to be heard and acknowledged. However, reality is far more complex, as our informants describe.

Social media has given voice to some (resulting sometimes in organizations losing their central role) but in other cases social media becomes a means for inclusion and a mode of communication (rather than being about giving a voice). The heterogeneity of the target groups, and the limits of the implementation of digital media, inevitably challenges the ideal of inclusion. An increased use of digital media is perceived as a risk of exclusion of members due to a digital divide, i.e. a divide between those who have access to information and communication technology and those who do not. Such a divide also includes contextual factors such as economic, technological and cognitive resources (cf. Hilbert 2011, 2014), which to various degrees affect groups within the field of disability – both positively and negatively. However, many people with disabilities also experience difficulties using the Internet due to e.g. inaccessible design of platforms and content (Johansson 2019). The risk of unintentional exclusion is articulated in the interviews, and the perceived and discursive marginalization of these groups is taken into consideration in the choices and strategies articulated by the informants and motivate a cautious – even though necessary – application of social media. The informants acknowledge the need to adhere to rather traditional media because many of their members are not active on social media. Thus, they are indeed aware of the democratizing potential of the Internet and a social media presence, but they also acknowledge the exclusionary effects of ‘going digital’. Based on the interviews, we identify an ambition toward democracy but whether it is possible to reach or not via social media would need to be addressed in further research.

Informants attach great importance to social media as outreach tools, but they also express a need for other means and media in order to reach and represent members who are not connected or engaged in online activities. This may explain why the organizations have to deal in their advocacy work with two sets of media strategies, some of which are more appropriately done online (campaigns, fund raising, engaging in debates of interest for members, raising awareness on disability etc.) and others that are preferably done offline (member information, staying in touch with primarily the elderly etc.). It is considered necessary to maintain offline tools, and a full analog-to-digital transition is neither relevant nor of immediate interest. This also highlights an inherent tension between, on one hand, seeing digital online activities as ‘necessary’ and as part of modern communication channels and, on the other hand, the fact that actions, engagements and communication largely take place offline due to members’ limited online presence.
Our conclusion is that social media challenges the traditional structure and the assignment of the organizations and that disability advocacy organizations in Sweden have increased the variety of channels for their work. However, their internet use and social media activities have not been able to re-design their relationship with members and their relatives. This somewhat paradoxical relationship is explained by reference to structural obstacles and circumstances that prevent the advocacy organizations from engaging more extensively in online interactions and communication with members. Most, if not all, organizations analyzed in this article are using basic online strategies and communications tools. For instance, they reach out and bring awareness of the organization’s causes and members’ situations, engage in disability-related issues through campaigns and let themselves ‘be seen’ by current and potential members.

Taken together, our findings suggest that members with disabilities are primarily considered as information recipients rather than content producers in online activities (cf. Lovejoy, Waters, and Saxton 2012). Our findings also suggest that generalizations about the Internet and social media presence and activities as tools for empowering people with disabilities are ill-advised (Trevisan 2014; Ineland, Gelfgren, and Cocq 2019). Online activities are seen as important and relevant, especially in a mediatized society and when connecting to youngsters, but at the same time counterproductive through the risk of introducing and emphasizing new divides (now digital) within their communities based upon, for example, technological, economic and cognitive resources.

Given the informants’ key roles in online communication and initiatives, an important issue for further research is to determine if and how disability advocacy organizations in Sweden are increasingly professionalized and potentially distant from those whom they seek to represent (cf. Barnes 2007; Trevisan 2014). Another question for future research is that although disability advocacy organizations take pivotal roles in formulating agendas and activities on digital disability issues, little is known about what people with disabilities themselves see as important questions in advocacy work. To what extent do advocacy efforts among disability advocacy organizations support the goals and agendas of members? We consequently call for further research from a disabled person’s perspective. This would complement this present study with valuable insights into for instance how online strategies might offer possibilities or limitations in advocacy work for people with disabilities who are not actively engaging in online activities.

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