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Blind and Online

An Ethnographic Perspective on Everyday Participation Within Blind and Visually Impaired Online Communities

Olivier Llouquet

...disabled people are continually being written out of the future, rendered as the sign of the future no one wants...It is my loss, our loss, not to take care of, embrace, and desire all of us. We must begin to anticipate presents and to imagine futures that include all of us.

Alison Kafer, "Feminist, Queer, Crip."

INTRODUCTION

The rise of the internet as a global network for human exchange is deeply transforming our lives. As more people around the world connect to the network and make it part of their everyday life, the potential of technology to enable knowledge sharing and facilitate inclusive forms of interactions and social participation has never been greater. However, the so-called "informationalization" of society is "intertwined with rising inequality and social exclusion throughout the world" (Castells 1996; in: Goggin/Newell 2003: 68). In particular, Chaudhry (2005) suggests "visually disabled people are arguably the marginalized group most drastically affected by the information technology industry because of the visual bias of so many ICT products."

This paper adopts an ethnographic approach to examine the everyday participation of members of blind and visually impaired online communities¹.

1 | I use community here to refer to a group whose members interact with each other primarily via the internet. It should be noted that visually impaired people are as different from one another as sighted people are, and that I adopt the view of Barbara Pierce, President of the National Federation of the Blind of Ohio, in her article posted November 2008: "There is No such Thing as Blind Culture." cf. <https://nfb.org/images/nfb/publications/bm/bm08/bm0810/bm081007.htm>

Through online encounters, I attempt to look—with my informants—at how they appropriate the possibilities technology offers and the challenges they face in their everyday life. While these narratives are partial and incomplete, they are personal accounts of lives lived with a visual impairment. I discuss the methodological and ethical aspects of the research and reflect on how this experience has led me to expand conventional ethnographic methods beyond the visual.

METHODOLOGY

Ethnography involves the practice of spending time observing and participating in a particular environment—the fieldwork—and using a range of data collection techniques to describe human practices in that environment (Leander, 2012). With the rise of the internet, ethnographers (e.g. Boellstorff 2008; Miller 2011; Pink/Postill 2012) have extended the notion of fieldwork to encompass the ‘online’ realm of the internet, and social networks such as *Facebook* or *Twitter*.

Over a period of two months, I joined several *Facebook* groups run by and for visually impaired people (“VI”)². Groups vary in size, from a few members to more than 4000. Members are widely dispersed over broad distances, but most are based in European countries or the United States of America. The study is limited to groups using English as a language of communication.

I started the research focusing on assistive technology and joined the group: “iPhone and iPad Apps for the Blind and Visually Impaired.”³ In my required introductory post, I explicitly stated my role as an anthropologist and the objectives of the research. Within a few minutes I received a phone call through *Facebook*; I felt unprepared but decided to answer. The call was from John, from California. He is an accessibility consultant and ICT trainer for VI but he had just lost his position due to job cuts in his company. He tells me about his experience working as a technology trainer and confirms the popularity of Apple devices amongst VI. John was born blind, and he says maybe that is why he does not care much about photographs and does not use a profile picture. He says his friends know who he is, so a picture is not required. For him, the group is a great place for hanging out, and hearing about other VI daily experience.

After two weeks spent gathering technical information on assistive technologies, I joined groups where people engage in more personal inter-

2 | I make use of this term as members commonly employ it.

3 | <https://www.facebook.com/groups/iPhoneiPadAppsfortheBlindVisuallyImpaired/>
Accessed: March 2016.

actions. The group⁴ in which I participated most regularly was created in July 2015 and has since gathered a steadily growing membership (nearly 3,000 members at the time of the research). Publicity for the group is gained mostly through word of mouth and the promotional efforts of its administrators, who are all visually impaired. The group is not reserved exclusively for people with visual impairment, but the majority of users are VI. However, it is a private group and one has to ask to join. Once accepted by an administrator, new members are invited to read the group rules, posted permanently at the top of the group Wall. In particular, members have to use their real names and should not send friends requests to persons they have not previously interacted with. Administrators have the possibility to exclude sighted “spammers” who “add friends to only send scams,” or anyone who does not comply with the rules. Observations were based on every day interaction through *Facebook* and also private interviews. I usually spent a couple hours per day engaging with members on the group Wall or messaging privately through *Facebook Messenger*. Over the course of the study, no surveys were conducted; seven semi-structured interviews were held over the phone through *Skype* or *WhatsApp*, ranging in length from thirty minutes to two hours. By way of response to the issue of the “researcher gaze”—discussed below—I decided to only interview participants who reacted to my posts or comments or befriended me, therefore signaling their willingness to interact.

The study is independent of parameters such as gender, age or country; it represents a sample of online encounters that reflect the availability of participants and their willingness to engage with me. For each interview, I sought authorization to record the conversation and the informed consent of the participant toward the publishing of the edited recording; I also asked for permission to use audio extracts and quotes—transcribed in written form and made anonymous.

A BRIEF OVERVIEW OF ASSISTIVE TECHNOLOGY

In 1998, Section 508 of the Rehabilitation Act of 1973 required Federal Agencies of the United States of America to make their electronic and information technology (EIT) accessible to people with disabilities. According to this section, “an accessible information technology system is one that can be operated in a variety of ways and does not rely on a single sense or ability of the user” (United States Department of Justice, Civil Rights Division, 2009).

4 | For data protection, this group will remain unnamed (otherwise administrators could be easily identified).

This amendment was a high commercial incentive for multinational companies to include accessibility features in their operating systems if they intended to sell products to the US Government (cf. Brown/Collier 2015). This sparked the development of commercially affordable, voice-aided Assistive Information Technology (AIT), also referred to as “screen readers.” By reading on-screen text through a voice synthesizer, screen readers greatly facilitate electronic communication and basic browsing. However, since they are limited to text, many graphic interfaces remain unreadable and make the navigation an arduous task, especially since online content is moving toward more visual media—like GIFs and videos—that cannot be interpreted by screen readers.

Many times people make an image with a message on it, when really it could just be words and this is very annoying.—Abbie

Since 2005, all Apple computers have come with a built-in screen reader called *VoiceOver*. From 2009, *VoiceOver* has been available on all iOS mobile devices along a screen magnifier. This has been a milestone for VI users as they were able for the first time to use the iPhone, a mainstream device, without the need to purchase additional assistive third-party technology. Many users expressed their appreciation towards the brand.

I am a big Apple fanatic. I live and breathe Apple. I have an Apple watch on my left wrist, an Apple wristband on my right. I have Apple socks, even Apple sneakers. I have an Apple Shirt and never take it off. I have Apple glasses, and I also have an apple tattooed on my left arm. – Miko

The progressive shift to mobile devices, in combination with GPS and geo-located services such as *Uber* or *Google Maps*, brought another positive evolution in terms of mobility. Latest innovations include apps like *TapTapSee* or *CamFind*, which utilize the recent advances in artificial intelligence together with use of the camera, identifying anything taken with the phone or—in the case of the more recent *AiPoly Vision*—through real time video. They replace the first generation of apps, such as *BeMyEyes* or *VizWiz*, which relied on sighted volunteers to help identify things via video calls. These particular advances allow a more independent social life.

I sometimes use *CamFind* when I am at a party, to take a photo of the drinks in front of me and to know what’s available, so that I don’t have to ask someone else. – Abbie

While technological innovation has improved conditions of life for many blind or visually impaired people, there is also growing concern over dependence on

technology. Members often discuss the impact of technology on their life and reinforce the importance of Braille literacy.

The majority of people now are so reliant on their technology. I consider myself as a bit old-fashioned but if someone told me to get rid of my laptop or phone for, lets say, seven days, I would find it very difficult. – Fabian

An informant also pointed that while technology has solved many problems for VI, a tendency to technological determinism often masks the social reality of living with disability.

People would say, “isn’t it amazing what technology can do?” Or, “isn’t it amazing what medical science can do?” But they don’t really know what is there. They just know there is stuff out there. They don’t really connect with it. There is a presumption that technology solves everything. The problem is that people assume that because the technology is there you can do anything. – Daniel

The problem is not necessarily simply what is accessible to VI, but the ignorance of the existing support structures.

The main problem is that my blindness is a problem for others. It prevents me to get into jobs because what tends to happen is that people would think hiring a visually impaired person would cost too much, but it is not necessarily true. For example a lot of employers in the UK don’t know about the access to work scheme, which provides financial support to buy assistive technology⁵. – Fabian

Most of members use a profile picture and therefore ascribe to the form of visuality inherent to social networking sites. Being social through this visual medium requires members to engage in specific strategies to portray themselves accurately. A common way is to ask a sighted friend to take a photo with one’s phone. Fabian, a freelance radio host, uses a staged photograph to represent himself; he portrays himself wearing a pair of headphones whilst talking through a microphone and using a laptop and audio mixer.

If you want to change your portrait or the way you present yourself, how do you make sure that you do that accurately? For example, I started growing a beard. Now I know that it needs to be tidy, it needs to be “presentable”. So particularly as a visually impaired person, on a visual basis, if you want to consciously change your portrait how do you do it in a suitable way? – Daniel

5 | In the UK, an Access to Work grant can pay for practical support for workers with disabilities. cf. <https://www.gov.uk/access-to-work/overview>

SUPPORT GROUPS

Isolation is a common issue with people living with disabilities. Group members reach out to other members. They can either write to the entire group, or message each other privately.

I think isolation happens everywhere actually, but US is a very big country. Many blind people live in places that are very rural because it is cheaper there and they don't work. As a result, they don't really have anyone to talk to, or sometimes they also have other conditions beside blindness, and that makes them very isolated. – Ava

Most people are cautious and will generally interact first through the public Wall to get a sense of who the person is before accepting a friend invitation.

If I think they're a bit dodgy, I don't talk to them. For instance, if I get a friend request on *Facebook* and I don't know the person, I would always message the person and ask why are you messaging me. – Isa

Support groups on *Facebook* allow members to engage in social interactions more frequently and develop an informal virtual support network.

What I love about this group is that when I have a problem/question regarding the computer or devices that I use, as soon as I post the questions...bam! People help right away. Great technical support! – Ava

Sometimes members may feel like starting their own group based on shared interests, goals or age; some groups gather a following, other stagnate or are abandoned, forming a complex ever-changing network where the private and public are interwoven. Most members interact privately within their personal network of friends. As the study progressed, I joined other groups created transversally on other platforms such as *Skype* and *WhatsApp*. These groups were effectively smaller and more private, because members need to provide their *Skype* ID or phone number in order to join. Also, these channels imply a more intimate exchange, since members engage with each other through voice. Participants post voice messages regularly as they are engaged in their daily routines. It is an effective way to fight boredom and be involved with things, as well as maintaining a regular contact.

Other important sites of the blind digital “ecosystem” are the many online community-based radio stations such as *Dodge Radio*, *Mushroom FM* or the *VIP Lounge*. These stations are significant as they offer “a place to make friends,

find out about current trends in the VI community and help people who want to become broadcasters” (*VIP Lounge* website)⁶.

The *VIP Lounge*, a global community-based radio station for the visually impaired, has fostered an innovative network linked with chat rooms on *WhatsApp* and *TeamTalk* platforms. According to one informant, it could have close to 10,000 members worldwide.

EMERGING SITES OF POSSIBILITY

In their on-going decade long anthropological research on disabilities, Ginsburg and Rapp (2015) argue that “making disability count requires attention to sites of cultural production that reflect a growing desire to communicate about the reality of living with disability in arenas of representation.” They continue by noting that “‘the disability publics’ [they] are studying are building new social imaginaries in which people with disabilities have horizons of possibility.” The sites they engage with in their fieldwork are cultural entities—such as museums, educational structures, dance and theater projects or film festivals—but I believe their approach could be extended to online communities of people living with disabilities. For example, some members are experimenting with the live feature of *Facebook*, broadcasting themselves and performing in front of the camera. A group member proposed to organize a multi-located real time concert on *Skype*. Musicians and singers upload videos, poets share rhymes, writers post extracts of their stories; transforming the Wall into a stage for creative experimentation. Besides an arena for creativity and entertainment, *Facebook* groups also are public forums where “members can voice their concerns, release the pressures they face in their daily life and engage in a collective rewriting of what could be a life lived against the grain of ‘normalcy’” (Ginsburg/Rapp 2015).

Here’s a question for you all. Do you get bothered by your family, friends, and/or strangers making jokes about your blindness? It can be small or something big but how do you feel and deal with it? My dad for years called me blind bitch. He apologized after I told him that had always bothered me. I don’t know if it was a sincere thing or not, but that got to me a lot since he picked on me about other things about myself. My siblings did things as well at times [...] sometimes I remind them and sometimes I don’t bother giving into they just don’t realize how much it hurts me. My mom the other day commented on my outfit cause some colors were a bit off and she was like “oh just tell people your color blind.” I laughed it off and she was like “see, you find our jokes funny,

6 | <http://theviploungeradio.com/> Accessed: March, 2016.

it isn't that big of a deal to you." I didn't feel like arguing over the matter and let it go. - Post on the group Wall.

SENSORY ETHNOGRAPHY

In a reflexive review of her ethnographic research on blindness, Gili Hammer (2014) reflects on the ocular-centrism characteristic of most qualitative methods, and questions terms such as "participant observation" or "the researcher gaze." She asks: "What are the sensory dimensions of the ethnographic project? What does participation-observation entail? And can participant observation be ethical when my informants do not have the possibility to know where is the 'researcher's gaze'?" (Hammer 2014).

Although Hammer's research took place "offline," I felt the same ethical and methodological questions surface during my online study, conducted remotely. As a sighted user of an interface designed for optimal visual control, I am—*de facto*—in a situation where I possess more information than my informants.

The visual interface has been optimized for the visual scanning of information. Space on the screen is a fixed, detailed and stable entity divided in areas associated with specific functions. The center of the screen is reserved to browse through the archive: Time is contained into space, and scrolling down effectively makes one move back in time, revealing archived public interactions that have taken place till the very first post. What is written here stays forever. While sighted users can quickly browse through the timeline, accessing the information through screen readers would take a considerable amount of time. - Extract from research diary

Boellstorff (2008) advises that ethnographers adopt the principle of care as a response to "the asymmetrical power relations and imbalance of benefit between investigator and investigated" (ibid: 129). With this in mind, I progressively became more aware of the challenges faced by visually impaired people. I also reflected on my own bodily engagement with the machine and noticed my attention shifting from the visual to the auditory in order to make sense of the information:

It feels more natural to close my eyes. It helps me to focus on the conversation, to feel the richness of the voice of my interlocutor. I notice the changes in intonations, the pauses and silences, the rhythm, the accent. Acoustic intimacy. I can hear voices in Chinese coming from a show on TV playing in the background. The static noise reveals the derelict state of the Eastern European network; calls from Africa are incessantly dropped. A layering of synthesized voices and digital sounds, fragile and precious traces of ephemeral encounters on the network. These groups are like sound oases in the vast

ocean of images that is the internet. Here, it is the sounds themselves that create time and space. If there is no sound, nothing happens... – Extract from research diary

CONCLUSION

Lack of awareness, poor public policies and the visual bias of ICT products make content difficult to access for visually impaired users. However, blind and visually impaired online communities are support groups through which members enrich their technical and social capital. They are emerging sites of possibilities where members collectively engage in the rewriting of disability and regain a sense of agency against the privilege of able bodies. To be able-bodied is—over the course of a lifetime—a shifting, transitory and uncertain state. The social model of disability has sought to redefine disability as a social problem, one that can be overcome through social change. As trans human communication technologies become more prevalent, it is critical that they remain accessible to all. In his book *Orality and Literacy*, Walter Ong (1982) suggests, “with telephone, radio, television and various kinds of sound tape, electronic technology has brought us into the age of ‘secondary orality’. This new orality has striking resemblances to the old in its participatory mystique, its fostering of communal sense, its concentration on the present moment...” (ibid: 133). The visually impaired groups offer opportunity to redefine how we imagine and use technology to interact with each other since the sensory and auditory sense are brought to the foreground. Sensory ethnography in particular, and the “sensuous scholarship” (Stoller 1997) it entails, can contribute to the exploration of alternative forms of sensory engagement with technology; thereby promoting inclusive, rather than assistive, technologies.

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