

Representation, Access and Contestation: Facebook and Vision Impairment in Jordan, India, and Peru

Joyojeet Pal^{a*}, Ana Maria Huaita Alfaro^b, Tawfiq W. Ammari^c, Sidharth Chhabra^d,
Meera Lakshmanan^e

^a*University of Michigan*; ^b*Pontifical Catholic University of Peru*; ^c *University of Michigan*; ^d
University of Michigan; ^e *Independent scholar. Corresponding Author- Email:*
joyojeet@umich.edu

This paper presents qualitative research on the use of Facebook by visually impaired people and organizations representing them in Jordan, Peru, and India. We found that individuals and organizations have very different motivations and pathways for using social media. Social media serve as a means to help individuals with vision impairments to expand their social circles, network with casual acquaintances, and find various kinds of social and technical resources independently. However on issues of representation we found that social media have the potential to play a double-edged sword, reinforcing in some cases the same stereotypes that individual users of assistive technology (AT) sought to overcome by using technology in their professional lives. We find that individuals often characterize social media and assistive technology in the same vein — suggesting that for many parts of the global South, the dramatic change in the means and ability to leverage social and professional possibilities has not come from any one technology alone, but from a broader evolution of the technological environment available to people with vision impairments. Access to social media and technology disrupt an environment in which social and economic spaces for people with disabilities are still a zone of contestation between a dominant discourse of vision impairment enforced by generations of negative representations of disability, and a new world of technology users challenging representations and assumptions as engaged, connected professionals.

Keywords: Social media; Weak ties; Social capital; Visual impairment; Independence

Introduction

The othering of disability is prevalent in mainstream news and entertainment media. The consequent violence of reductionism minimizes complex issues inherent in the representation of a group as an ‘other’, cementing notions of disability as a monolithic state of being incompatible with the ‘normal’ (Kriegel, 1987). Work on the politics of public discourse of

disability has examined issues of gender (Shakespeare, 1994), race (Omansky & Rosenblum, 2001), and orientalism (Barker & Murray, 2010) in the images and text that have come to construct the popular discourse of disability in our societies. The representation of disability online is different from that in traditional media in that despite the existence of powerful corporatized voices, online media are generally distributed and consequently the dominant lens on a specific topic may evolve very swiftly (Goggin & Newell, 2003). There has been a gradual growth of public consciousness of disabling imagery, and yet this awareness hasn't done away with old ways of perceiving and representing. The fragmented nature of media production has meant that the mainstream public understanding of disability, often itself rooted in the popular media imagination, is eventually reproduced in people's media production and circulation online. Thus the online representation ends up being a derivative of the offline dominant voice (Lee, 2012).

Social media such as Facebook are at once an area of representation and negotiation, both a means of both interpersonal interaction, and brand and image articulation (Joinson, 2008). The ways in which people and organizations use Facebook (which we focus on here) for personal purposes have been found to be distinct from the ways of groups working as spokespersons on disability rights (de Haan et al., 2014), or from the representations encompassed in images of disability that wind their way through social media as 'forwards' (Waltz, 2005). The act of explicit representation often comes through the articulated agenda of organizations working on disability issues and also organically, irrespective of the participation of individuals with disabilities in those representations. Likewise, several organizations that work on disability issues may be online for a range of purposes that do not include representation.

The largely visual nature of online representation on some of the more popular social media outlets, often lacking clear captioning or 'alt text' describing what is in the images, has meant that people with vision impairments themselves cannot access how they are embodied by the artifacts about them. The consequent separation of individuals from the production and distribution of images that represent them has contributed to a broadening politics of vulnerability in the media (Ellis, 2010). Facebook, for one, had a limited buy-in from people with vision impairments early in the product's history when it was primarily perceived as an image-posting site. As social media address increasingly became a calling-card of sorts, there was an uptake in the adoption of Facebook among people with vision impairments (Brady, 2013). Recent research by Wu and Adamic at Facebook found that the online presence of people with vision impairments is substantial (Wu & Adamic, 2014). Users with vision impairments are found to do much the same thing online as sighted populations do, but with slightly less activity on photos, and a few significant differences distinguish their online behavior. First, there is a larger homophily effect based on the disability, i.e. there is a greater chance that one's contacts will likewise be using Facebook through a non-visual interface. Second, and particularly relevant to our research, individuals with vision impairments had a significantly higher chance of getting replies and starting discussion threads on posts they

made on Facebook (Wu & Adamic, 2014). However, one shortcoming of this research is the lack of representation of people with disabilities in the global South, where access to the assistive technologies required to maintain a presence online remains a major hurdle. Consequently, not a lot of work has examined the intersection of online spaces with either the broader representation of disability or the changing social and institutional access for people with disabilities themselves.

Studies of disability in the global South have found that a range of factors such as the lack of systemic access to independent living, cultural beliefs about the societal place of people with disabilities, and limited access to resource institutions impact the ways disability leads to social and economic marginalization, and that nuanced study of disability can help in the understanding of how these differences are operationalized in various locations (Groce et al., 2011). Disablement is tied with other forms of marginalization, rooted in the ways tradition has projected otherness (Ghai, 2001) or plight (Bazna & Hatab, 2005), and the exclusion of people with disabilities bears important similarities to the marginalization of people for identities of race, citizenship and gender throughout the world (Meekosha, 2006). But here we have an important intersection of marginalities- marginalization from the lack of accessibility is layered over challenges of living in a society of limited resources and a lack of targeted protections. Yet as discourses have stabilized towards national goals aggregated to the political and social mainstream, disability remains largely excluded from the agenda, particularly when compared to other marginal identities, including race (Graham et al., 2010), gender (Ghai, 2002), religion (Turmusani, 2001), and caste (Thomas, 2005).

Systemic negative representations have contributed to a popular 'visibility of disability' - or the perception of disability- in the public sphere by appeals for sympathy (Parashar & Devanathan, 2006). Such ideas reinforce the sense that people with vision impairments are fundamentally incompatible with a modern workspace (Sentumbwe, 1995). Access to technologies such as screen readers has been available through institutions such as schools and libraries for a few decades now in many Western nations, whereas these technologies are mostly missing through institutional sources in much of the rest of the world. Consequently popular media images of workplace integration, such as a blind person on a computer in an office environment charged with the same tasks as any other employee, are mostly absent in the global South.

A mix of recidivist ideas about disability and exclusionary approaches to building social and economic infrastructure helps cement hegemonic discourses of disability as fundamentally related to dependence. These affect the very foundations of social interaction on which economic participation is built. Poor architectural and social infrastructure impacts individuals' ability to maintain or expand their social networks. In turn, the social networks of blind people may largely be defined by the individuals to whom they have immediate physical access, via existing familial or institutional networks. The discussion of 'weak ties', which describes the connections between friends of friends and casual acquaintances, is

particularly salient here. The lack of these networks not only impacts the ability of people with disabilities to access and maintain weak ties, it also evokes the reverse impact of removing people with disabilities from the online social networks of non-disabled people. Weak ties are widely accepted as central to creating access to economic and social conveniences (Granovetter, 1973), thus being online offers the technical possibility for the individual to reconfigure control over his or her social presence by drawing upon a new set of virtual resources. These virtual resources are thought to lend people social capital, a term used to refer to the economic or social benefits of one's human networks. One's social capital can be seen as an indicator of one's ability to shore up social resources, whether economic or otherwise, through one's networks. Weak ties form a critical element of social capital by providing the frame for 'extended networks' because not all elements of one's networks can necessarily be close associates (Putnam, 2000). Social media offer various means of casual and group interaction such as 'status updates', 'likes', and 'tweets' through which one can interact with others with relatively low direct overhead compared to the viscerality of a phone call or a one-on-one meeting in the physical world. Consequently, there are more ways of staying casually in touch with connections that one may not otherwise engage with deeply in the physical world.

Putnam's work does not adequately consider the potential of social alienation of people with disabilities in an inaccessible physical milieu, particularly in parts of the global South. As Seale (2012) points out, digital capital alone is an insufficient frame through which to examine accrued value to individuals; people use their time online to build on existing cultural and social capital. Indeed, as group identities go, digital capital for the populations in our research begins at the point of being defined in othered terms by a popular media discourse of disability. As we find, online interactions can be a means of reinforcing these otherings since much of the pervasive discussion and image-creation of people with disabilities may be led by individuals or collectives that bring their traditional views of disability in society to the online milieu. Yet, as individual identities and motivations go, digital capital represents an entirely different set of possibilities for building and nurturing social resources that were otherwise unavailable.

For both individuals and organizations, social networks represent the potential of expanded networks and social capital on one hand and a means of representation on the other. These functions are tied; however, the former emerges as a stronger area of individual online motivation. Undoubtedly, questions of representativeness persist and organizations' use of social media as a space to negotiate the representations of disability is complicated by the fact that only a small elite group of people with vision impairments in low- and middle-income countries actually uses the Internet.

Approach and Methodology

The results presented here are from a comparative study of Bangalore, India; Amman, Jordan; and Lima, Peru, the objectives of which included the understanding of the role of assistive technologies (AT) and social media on access to social resources. The three cities were selected to craft a descriptive picture of three fairly distinct regions that have comparable access to similar technology and urban workplaces for people with vision impairments but represent a broad regional, cultural, and economic diversity. One part of the study focused on the intersection of multiple marginalities from a global development perspective (Pal et al., 2014), whereas here we focus on issues around social media.

Thus the instruments used to conduct this research gathered much data on social media use but were oriented to a broader goal of exploring the technology use environment of people with severe vision impairments. Two themes were eventually significant in a large number of conversations: aspiration and functional access. Conversations around aspiration centered on social and workplace objectives and the extent to which these were possible in the existing conditions in the respective locations. Conversations around functional access focused on ways in which technology entered an environment of exclusion, that is how technology created new conveniences, or sometimes reiterated existing forms of exclusion.

Representation was a meta theme that we explored primarily through a textual analysis of the Facebook pages of various organizations working with people with disabilities, but also through the transcripts of respondents' interviews. The convenience sample was restricted to urban adult AT users who were either in the workforce or close to joining the workforce, and such a universe automatically excludes people with the fewest economic resources.

Additionally, we used a survey with demographic modules and quantifiable information on individuals' places of access to technology, as well as self-assessment of various impacts of technology on independence, safety and socialization. This was followed by an open-ended interview. We conducted 176 surveys, and in 155 cases the interview with open-ended questions immediately followed the survey. In part due to the challenges in finding female respondents in Amman and Bangalore who met the criteria for selection, there is a gender skew in the data, as demonstrated in Table 1.

| | Male | Female | Total |
|---------------|-------------|---------------|--------------|
| India | 72 | 29 | 101 |
| Jordan | 17 | 8 | 25 |
| Peru | 26 | 24 | 50 |
| | 115 | 61 | 176 |

Table 1: Survey respondents by gender and country

All interviews were coded and triangulated by two independent coders per location. The codes were grouped to build themes. Four codes- socializing, independence, communication, and technology problems- emerge as the most commonly discussed topics; these themes are nested within the parent themes of aspiration and functional access (Table 2). Each of these lends a nuanced understanding of the ways in which people’s interaction with technology changes their access to services and also the ways in which the dominant social narratives around disability impact how technology gets appropriated and used.

| Theme | Number of interviews | General context and terms of discussion |
|---------------|----------------------|---|
| Socializing | 110 | Online and offline friendships, social integration |
| Independence | 131 | Role of AT / social media on sense of self-sufficiency |
| Communication | 72 | Role of AT / social media on network, communication |
| Tech problems | 82 | Challenges with technology use, assistance-seeking behavior |

Table 2: Key codes selected to inform themes in this study. *AT* assistive technology

Each theme represents a conversation in which respondents discussed an idea that indicated an impact or potential intersection with a technological artifact. Thus in socializing, people discussed ways in which their social networks were shaped with or before access to technology; on communication, respondents discussed issues around the nature and content of their communications with regard to technology use. The theme of independence includes respondents’ discussions around their control over their actions and social access, and the theme of technology problems was used whenever there was a discussion of challenges people faced with using technology, whether the social networks themselves or the tools that enabled their use. Although this was not explicitly in the research design, these themes repeatedly referenced social media as a means of social and economic access.

The analysis of interview transcripts was conducted prior to the textual analysis of public Facebook pages of organizations representing people with vision impairments. Discussions of representation emerged in many interviews, especially in terms of how individuals saw their own social media use as distinct from that of the organizations they were often part of. We

selected Facebook because it was by far the most commonly cited social network among those respondents said they actively use. Other social networks cited include Orkut, MySpace, and BlindWords.

Besides social media sites, many respondents used mailing lists, which were often the gateway to social media, especially for the older users of assistive technology. Mailing lists were discussed as offering a push mechanism for specific messages that needed a response as opposed to social media, which were perceived as relatively casual. Users who started using screen readers in the years following the ubiquitination of social media were more likely to start a Facebook account, often simultaneously starting an email account. In our sample, 110 of the 176 people interviewed had been AT and internet users before social media became popular. In contrast, a smaller set of 20 respondents, ‘AT millennials’, never dealt with the inaccessibility of other social media because Facebook had become a norm by the time they were online.

To complement the interviews, we analyzed the public Facebook pages of organizations working with people with disabilities, including:

Peru: Unión Nacional de Ciegos del Perú or the Peruvian National Union of the Blind (UNCP), Sala para Invidentes ‘Delfina Otero’ (SALA), and Infolector.

Jordan: Higher Council for Affairs of Persons with Disabilities (HCD), Academy for the Visually Impaired, Jordanian Blind Association (JBA), the Friends of the Blind Association (FBA).

India: Blind People's Association (BPA), All India Confederation for the Blind (AICB), Indian Association for the Blind (IAB), Netradeep Pratishthan (NP) and Antardrishti Forum for Friends of Blind (AFFB).

Facebook sites of organizations were sampled based on the most active public footprint among Facebook sites identified. Henceforth we refer to them by their acronyms.

Technology access: exclusions in workplaces and other public spaces

Eighty-two (53%) of the 155 interviewed individuals spoke in the course of their interviews of using some form of social media. Social media were typically encountered through screen readers or magnifiers in our sample, though a few people noted using social media through sighted intermediaries. Screen readers, which convert digital material on a screen into audio or Braille output, are expensive technology; a desktop license for popular software like JAWS can cost as much as US\$1,000. Confirming past research, we found that our respondents in similar settings faced access challenges because of cost as well as language localization (McCarthy, 2013). Although there are open source alternatives like NVDA, these were not

used by any of our respondents as a primary screen reader. In India and Jordan there are language localization issues because of the poorer-quality audio output of text in Arabic or Indic languages, which have less advanced speech synthesis technologies.

Piracy of screen-reading software on personal machines is common, but such piracy is frequently disallowed in the organized workplace. This typically means the user has to manage with a free reader such as NVDA or use a demonstration version of JAWS, which runs for 35 minutes before the system needs to reboot, causing disruption to individual work and, in the case of networked environments, to the group's work. A suboptimal technology environment for the user can mean a loss of control over one's work and frequent reliance on colleagues for technical support. For someone dependent on screen-reader access, this could often mean requiring an organization to make significant technology decisions that impact other employees' work environment as well. Thus organizations that chose to use open-source office software such as Apache OpenOffice inadvertently created an operating environment that was more difficult for screen-reader users because screen-reading software typically works better with Microsoft products. When individuals are forced to use whatever organizations prefer, irrespective of how well those technologies are supported, it creates new forms of dependencies that often necessitate the individual's reliance on sighted colleagues.

The uncertainty about the kinds of technology available in professional settings was an important push factor for seeking technology support on various social networks, both online and in the physical world. Community Service Organizations and disabled persons' organizations (henceforth referred to as CSOs), in particular, were integral in enabling access, particularly given the lack of AT through institutional sources such as schools, the state, and the workplace. The ability to 'manage for oneself' to every extent possible was important, particularly if the workplace could not be relied upon for access. Mobile or Web-based technologies consequently offered an important element of independence. Yet, the independence enabled by that technology still needed to be supported by an institutional framework that was often not quite prepared. As with employers unwilling to spend money on JAWS for blind employees, casually entering a public Internet center or cybercafé, a typical place of social media access for people across the board in all three countries, was no guarantee of being able to get online in an appropriate environment. Even if the individual came in carrying the requisite software, there was no guarantee a cybercafé would allow it:

They [employers] think that because it's something new [screen-reader software] it will spoil the [computers and] materials or something like that. Even if you go to cyber cafes, they don't want to install JAWS or even NVDA, which is portable, which you can carry on your USB stick. You remove the program and it doesn't affect the computer. Respondent 25, Female, Peru

In both India and Peru, we found that CSOs were integral in offering a range of AT software, training, and even bundled deals for technology (Pal et al., 2013). As a result, CSOs were also key elements in the decision-making of blind people with regard to technology or social

networks. In our sample, respondents were frequently the first generation of blind people in their respective locations to have access to computing. Many had grown up attending schools for blind people that had little or no technology, though in recent years it was through CSOs that they often accessed AT for the first time, as is shown in Table 3. Consequently, the CSO served as a central point of both access to AT and initiation into social media. Many respondents got their first email addresses while part of a CSO, and likewise their first social media accounts. CSOs were particularly important spaces for those in greatest need- 42% of the people in our sample who were without work got their sole access to technology through CSOs. But in turn, the CSO and its perspective on disability issues played an important role in the ways individuals were introduced to social media, for instance who their first layer of “friends” would be on sites like Facebook, and consequently how social media itself would extend or replicate individuals’ networks.

| | Male | Female | Total |
|----------------|------|--------|-------|
| School | 19 | 9 | 28 |
| College | 7 | 4 | 11 |
| Home | 25 | 10 | 35 |
| CSO | 44 | 32 | 76 |
| Computer class | 10 | 2 | 12 |
| Office | 9 | 3 | 12 |
| Other | 1 | 1 | 2 |
| | 115 | 61 | 176 |

Table 3: Location of first access to screen readers.

In all three locations, respondents pointed to negative portrayals of people with disabilities in the news and entertainment media. As research has shown, these negative portrayals lead to greater channeling of people with disabilities into certain occupations such as casual vending, massage, lottery sales and telephone operation (Pal et al., 2013). Unlike what may be typical in much of the global North, respondents noted first using screen readers after their secondary schooling. The resulting increase in aspiration can be seen as a re-imagination of one’s possibilities and capabilities away from an environment of information access restricted by

the production of Braille or audiobook materials. Getting a Facebook account dramatically increases access to media, by way of media downloads such as books, articles, or software, or simply through informative casual contacts who point one toward resources. The new recognition of one's enhanced information environment, and the professional environments of those within one's social networks, increases awareness of the gap between one's capabilities and what the workplace expects blind people to be able to do. This results in frustration in the lack of recognition in the workplace that blind people can do the same job as their sighted counterparts. In one case, a female respondent who happened to be an AT trainer at a CSO for blind people got a human resources position at a tech company. Given her position, she was keenly aware of the kinds of work people at the CSO got versus the kinds of work her connections on social media had. Consequently, her resentment was accentuated by the persistent patronizing attitude shown by employers:

I was not allowed alone to the washroom also. This had put me in depression and I started suffocating in the office premises. I would attend all the meetings, but with special attention. Once I could not resist, and dropped a mail to the director and the reporting manager, begging that I also want to be given responsibility, and I can perform. I got a reply saying that he was 'worried to give you stress'. Respondent 1, Female, India

As with respondent 1, the sense of shared identity emerged as an important element of professional choices and awareness of what does or does not count as a reasonable workplace. Early adopters of AT influenced the technology choices of others, particularly through connections at CSOs. But the existence of social media enabled new forms of building shared identity, including for people who were never part of CSOs, either due to a range of structural factors such as lack of physical access, or in some cases because disabilities were acquired late in life and individuals consequently did not self-identify as persons with disabilities. The pathbreakers — the first few individuals with severe vision impairments to be employed in specific sectors of work or companies — serve as exemplars for the community as a whole. For instance, we found that in India, when a few people got jobs as medical transcriptionists word quickly spread on Inclusive Planet, a social media outlet, and word got around on the CSOs training people for medical transcription and firms hiring for the same. In all three countries we found discussion of 'companies that hire blind people', ones that gained a reputation for being disabled-friendly. When asked about work aspirations several respondents named one or another firm, usually a multinational company, as the place they would like to work long-term. Because of social media, there was also the factor of individual persons who came to be known within the community because of repeated postings on Facebook or mailing lists. One such person who was referred through his reputation on mailing lists as a stenographer-turned-programmer came to be a champion for blind technology professionals online in India:

Due to my knowledge in technology, I am known all over the country; previously this was not possible; I was just an ordinary stenographer. But now I have gained some reputation

and some good name ... I am [now] seen as a worthy person in the office; there is the recognition and with it a lot of responsibility comes- this makes us more committed to the work. Respondent 59, Male, India

Respondent 59's nodal position on Facebook was not possible in his previous role as a stenographer operating in a relatively isolated environment of his own workplace. His use of the phrase 'makes us more committed' emphasizes a collective attribution of work ethic, assigning himself the place of speaking for his fellow blind professionals. The shared experience of workplace exclusion makes the individual's experience a reference point for the discourse on employability. The interwoven nature of the CSO role in starting up and representing the network, and then the individual as being a nodal point but also a model for the community, emerges in his experience. The social networks provide a channel through which anecdotes, connections and commentary spread. The CSOs are not replaced but rather are appended with a new means of information-sharing on employability and social engagement.

Participation in social networks also created an important sense of commonality with the daily experiences of others at the workplace. Respondents' use of the same technologies as their sighted counterparts often came as a surprise to some, and although sharing Facebook messages was a good start, the technology was still just one piece of a larger ecosystem where sighted people often did not have people with vision impairments in their immediate connections.

Online Representation

The important role played by CSOs in the access to services, training, and networks for people with disabilities puts them in a central place for defining the networks of their client populations. Consequently, we found that CSOs are major conduits for both starting social media accounts and for populating one's networks. Social media were found to be an important means for CSOs to emphasize their presence to the population they work with, as well as to the broader outside world, thus activity on their Facebook pages plays a role in driving adoption while at the same time connecting people with similar experiences:

There was a Facebook page for the academy I am working in and we all made 'like' to it and then we could talk to each other more or less daily. Then, after we all became connected through the page, we started asking each other for example, what the posts that were online actually meant, etc. Respondent 17, Male, Jordan

The 'likes' reinforce the credibility of the organizations and their reach. In both India and Jordan, we found that logins and activity were often controlled by sighted assistants at CSOs rather than by the users themselves. In both countries, respondents spoke of sharing passwords to email and social networks. The notion of 'likes' thus problematizes the end-audience of the social media presence. Images from the Blind People's Association (BPA)

Facebook page (<https://www.facebook.com/bpaindia1>) often consist of blind people alongside captions intended to appeal sentimentally to visitors to ‘like’ their Facebook page (Figure 1 below). Ironically, the image in this example had no text description, so it was inaccessible to someone using a screen reader. Likewise, the two largest Web presences in Jordan- Higher Council for Affairs of Persons with Disabilities (HCD), and the Jordanian Blind Association (JBA)- both had pages primarily populated by system administrators with images that highlighted the respective organizations’ achievements. Consistent with the results of research on CSOs’ online strategies vis-à-vis promoting their cause, these groups aimed to get as much ‘visible’ support as possible (Lovejoy, 2012).



Figure 1: Facebook page of the Blind People's Association (BPA)

In Figure 1, the image of a boy named Rohan exemplifies Tom Shakespeare’s description of the visibility of disability: ‘Disabled people could also be regarded as Other, by virtue of their connection to nature; their visibility as evidence of the constraining body’ (Shakespeare, 1994). Rohan’s construction in the image as an ‘other’ and its accompanying text reinforce the idea that his voice and visibility are provided by the sighted site visitor who ‘likes’ the page. Similar images have been featured in the BPA India cover photos, each accompanied by a ‘like’ request. As in Jordan, a majority of the content includes images without captions, and postings are typically from administrators and non-disabled viewers. We found the coalescing of groups around highly active individuals on Facebook to be similar to use patterns observed on mailing lists. A few key central figures in networks sustain the regular flow of information, particularly work-related information:

I have subscribed to the Visually Impaired Bankers group; in this site a manager from RBI [Reserve Bank of India-Central Bank] is the moderator; he sends us all the RBI news. He will upload the circulars and all other materials concerned with banking; he will send them through attachment; if any new VI join the bank, he will apprise them on what are the areas VI can work. Respondent 47, Male, India

The quote above signals the importance of banking jobs, which have historically had quotas for people with disabilities but also are stable career positions. The workplace nature of Facebook posts emphasizes a few important distinctions among the three countries. Although we found that Facebook posts in India and Jordan were primarily related to events and personal updates, mailing lists were talked about more often as sources of job postings. One social network with a mailing list feed that was mentioned repeatedly in India was Inclusive Planet. The site inclusiveplanet.com was set up by a group of lawyers and activists as an advocacy and social forum, and had a very active forum on a range of topics such as technical assistance, job posting, and file sharing. Though file sharing was a large part of the activity on (the now defunct) inclusiveplanet.com, the Facebook page focused on matters of policy and representation. The distinction between the two was crucial in one other fashion-inclusiveplanet.com was almost entirely used by people with vision impairments, whereas Facebook had a significant outward-facing component. As demonstrated in Figure 2, Facebook's appeal was used by the organization to discuss inclusiveplanet.com.

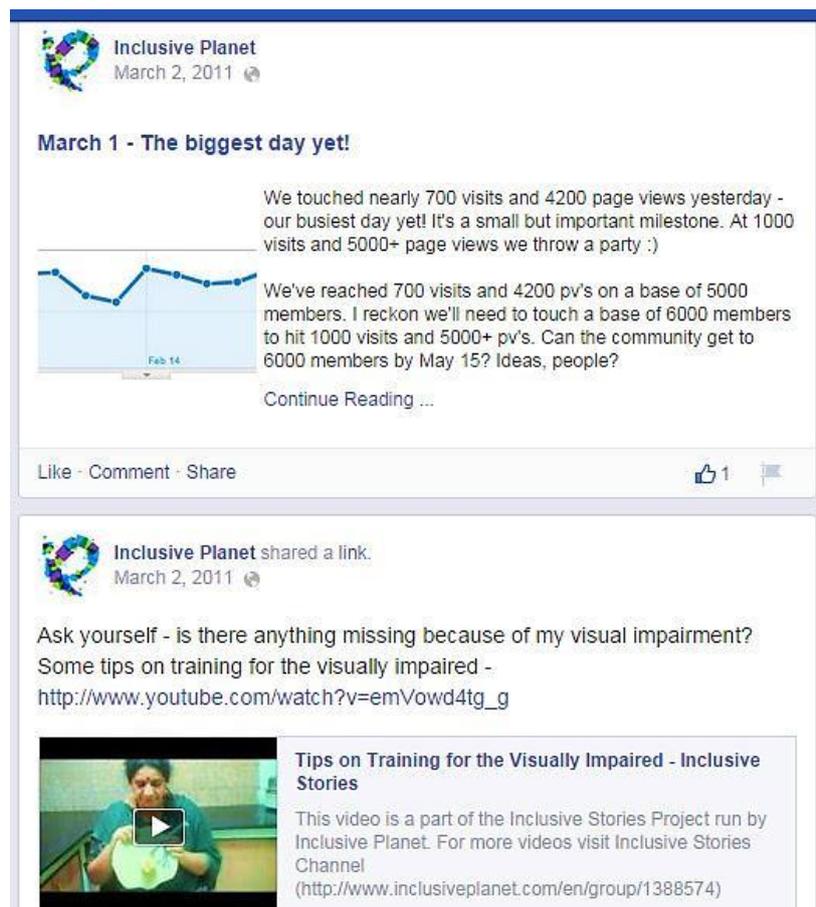


Figure 2: Facebook page of Inclusive Planet

As opposed to the discourse on the Blind People's Association page, the framing of discussions on Inclusive Planet, set up by human rights lawyers in India, is spontaneous and conversational. In a series of multimedia clips, people talk about their experience, drift in and out of subjects, much as anyone, irrespective of disability. The videos are on a range of topics of wide interest to people with and without vision impairments. The casual tone underlines an important departure from typical 'othering'. For instance, in a series of interviews on 'Advantages of being visually impaired' a group of young women had a spirited, funny discussion about what is good about being blind. The pages encouraged public comments, and the Facebook page eventually served as a discursive space about what it means to be blind, in this case as a woman with untraditional prospects:

If you are a girl, within 20 years you get married. It is only because of my blindness I can study up to this level. Otherwise I would have two or three children (by now). Excerpt from a narrative posted on the Inclusive Planet Facebook page

In India we found a significant gap between the Facebook self-representation of groups that had advocacy as their primary motivation and those that were service providers. In Jordan, however, both large state CSOs and three non-state CSOs were mainly service providers focused on a more traditional role as a reporting forum for its achievements. Announcements used a language and style of official notices; typical posts included awards ceremonies, visits of functionaries alongside images of stakeholders conducting tasks on camera, and posts on religious matters such as Hajj visits for blind people. We found very little interactive commentary, and images were typically not captioned, thus inaccessible to blind users.

Although elements of exclusion from the workplace and lack of institutional support for AT were comparable in Peru to Jordan and India, one important distinction was the comparatively longer history of access to AT in Peru. In Lima, the National Library is an important place of public access to AT, equipped with Braille displays and screen readers. The *Sala para Invidentes Delfina Otero* (SALA) and the *Unión Nacional de Ciegos del Perú* (UNCP) were among the more followed Peruvian CSOs on Facebook, with 1,900 and 4,300 followers, respectively, at the time of this report. SALA utilizes its young user population and online presence for casual postings and introductions, and to announce events such as dances or sports, whilst the activity on CSO pages like that of the UNCP are dominated by administrator posts.

Figure 3 below, a Facebook page for a Peruvian CSO, represents a contrast with the images of BPA in India. The Peruvian image of a dance class for blind people does not make a sympathy appeal. Alongside the ad on the Facebook posting, there is a detailed text description explaining the dance class and its purpose. The intended audience thus is both sighted and print-impaired individuals.



Figure 3: Facebook page of the Sala para Invidentes Peru shows an advertisement for a dance class

The distinctions among the pages are reflective both of the organizations themselves and the audiences they reach. The inclusive tone of SALA was articulated by an informed core within the user base, and by its being housed in a public library with a history of extending inclusion to various marginal groups in Lima. Inclusive Planet, run by a group of activists trying to move away from a medical model of disability, tried to create a space to re-evaluate the popular discourse of disability, yet unlike SALA its audience on Facebook was primarily sighted. Similarly, BPA in India and JBA and HCD in Jordan were driven more by the state or structures to attract funding or highlight achievements, and consequently projected an entirely different discourse.

New Networks and Ties

In India, Jordan and Peru, alike, respondents spoke about restrictive social networks in relation to a combination of factors- lack of access to institutions and infrastructure, limited access to information sources, and persistent cultural beliefs that overlay attitudes towards

inclusion. Institutions such as schools, CSOs, and government agencies, were discussed as central to the transition from formal education to workplace. Schools for blind people were seen as a primary social network, and graduating meant losing regular contact with cohorts of friends. In regions where comparable social spaces for adults do not exist, graduating often resulted in individuals being restricted to their domestic spaces. The making of new connections was limited by who one could approach, and the persistent cultural segregation of people with disabilities limited the number of non-disabled friends in social circles. This exacerbated the sense of isolation away from the mainstream. Assistive technology and social media were seen as a way out of the isolation:

Just imagine how was our life 15, 20 years before. Telephone was not reaching to everyone, there was no cell phone at all; of course in India, telephone booths were not reachable, you couldn't reach them easily and you had to rely upon the post mail. ... All our contacts was through letters and you had to wait, once you write the letter you have to wait that letter to reach for whom ever you were addressing and to get response another three days, one week if everything goes well; otherwise you never know, when you get to hear from them. Same thing would have happened with us if we had no technologies. My friends circle would have been very, very small. Respondent 91, Male, India

Besides the communicative efficiencies offered by AT, respondents described the ability to connect, and stay connected with, casual connections at their own will as being very important. This was a change from the past, where the ability to initiate communication could be limited by the means of approaching new connections and by the channels of providing private conversations. Screen-reading technology removed the human intermediary and gave the individual privacy and agency on creating connections. The limited awareness about screen reading in the mainstream meant many new connections started with something of a surprise:

Some people get surprised about it. [Someone told me] 'I could give you my email, we could stay in touch, and I could send you some things if you could use a computer.' [I said] 'Hey, what's wrong with you, I can use a computer, just send it.' Then they get surprised, and I explain 'there's a program that can read and we can use a computer, we can communicate.' Respondent 28, Female, Peru

The ability to pull connections at will through Facebook came up in similar terms to email, as an indicator that one could communicate in ways that had become the standard for society. The lines between social media and the affordability of access to the Internet and mobile telephony blur as people characterized the overall environment of being connected as what was central to their new social environment. Organizing connections was an important means of staying in contact, and a way of getting referrals to new, more casual acquaintances:

[In] 2004 I did not have much big circle, I don't know anyone out of my particular contact. Today I have very huge contacts, I have about 625 friends on Facebook, and some 600 or 700 odd followers on Twitter, whomever I know. It's not that I know those people only; I know a lot of people like when I attend an event, so it's the Internet feature. It's a big boon; it's an evolution ... it gives access to everything what I don't have at my immediate catch. Respondent 96, Female, India

Early circles of online friends were often populated by immediate networks, particularly when individuals were affiliated with CSOs that had active online Facebook presences. People who had recently acquired vision impairment said that social media helped build new circles, particularly among those who could offer technical and social assistance. For these individuals, affiliation with a disability CSO was not universal because they may not have been concerned with disability issues prior to their own experience. Indeed, late-life disabilities and social media is a topic in need of greater examination. At least three people in our sample from fairly well-to-do backgrounds acknowledged living 3–10 years without any knowledge of AT after losing their vision- in part because they simply had no blind people in their social networks to begin with. This is indicative of the segregation of disability in society right from schooling upward. In these cases social media were seen as the main route toward connection, as this respondent explained:

When I lost my vision, I was not in touch with any association or organizations. Then when I went to them, somehow I did not feel like contacting them; I felt them quite orthodox type, so I never went to any associations. I know many VI — all who are into IT, and it is only because of screen readers and Internet and not because of any association. As I am able to access social network, I am in touch with many people across the border. Respondent 71, Female, India

Facebook can be particularly difficult to navigate on a screen reader because of its very visual and click-based interface, its lack of captioning culture and its rapidly changing environment of applications and interactions. Respondents noted that technical assistance was an almost ongoing need because interface environments change constantly. Finding expert users within social networks either with navigating the Facebook interface, or with AT in general, was found to be difficult. Most AT training comes through institutional sources like CSOs and educational institutions, which rarely cover specifics with social media interfaces, as this woman discussed:

One difficulty for blind people will always be to upload pictures, because how do you choose these? ... There's no institution that teaches us these things for blind people. A person that sees doesn't need to be taught how to use Facebook; he uses the mouse and can handle it perfectly but for us, it's not the case. We have to find shortcuts with the keyboard; we have to check compatibilities among the programs and those things we learn by practice. Respondent 13, Female, Jordan

Accessibility on image-heavy social media is not new, and products like MySpace and Hi5 have performed poorly on screen readers even after reaching millions of sighted users. Facebook by its sheer reach has changed the social media space, making it more or less ubiquitous for individuals and organizations alike. It has become the norm for CSOs serving a range of populations to have some social media presence. The ‘likes’ artifact has become a metaphor for popularity, and the presence on Facebook itself has become part of organizations’ calling card. For individuals, the outreach through Facebook has broadened access to a community of practice around screen reading and the AT environment in general. Technical queries not only go out to a wider group of users but, more important, they stay posted for clarification and build reputations of the individuals who have the answers. So access to social media has become an essential component to learning more about assistive technologies in general, as this respondent described:

When you get to use social networks, it became the main source to (stay) connected with old friends whom I had lost contact long ago. Also, it allowed me to know how the SR works better since these require special scripts so as to deal with them. Many of the people with low vision cannot make use of the FB because they do not know about the scripts that come along with JAWS, but have to be added separately. Respondent 20, Male, Jordan

Table 4 below shows that friends and online connections are the largest sources of technical help. The growing role of the online component suggests a movement away from a model of pulling assistance from personal networks to a more anonymous format of connecting, as needed, to a community of practice embedded in one’s online acquaintances. This move has impacted individuals’ sense of independence and control over technology choices. CSOs continue to play a large role in India, in part due to a weak state infrastructure and consequent early reliance on CSOs for support.

| | India | India | Jordan | Jordan | Peru | Peru |
|---------|--------|--------------|--------|--------------|--------|--------------|
| | Source | Not a source | Source | Not a source | Source | Not a source |
| Home | 20 | 81 | 7 | 18 | 3 | 47 |
| CSO/DPO | 55 | 46 | 1 | 24 | 7 | 43 |
| Friends | 65 | 36 | 17 | 8 | 29 | 21 |
| Online | 68 | 33 | 11 | 13 | 28 | 22 |

Table 4: Sources of help on technology issues. *CSO* Community Service Organization, *DPO* disabled persons organization

Acquaintances on social media were often a source of links to ‘cracks’, the term typically used for pirated media or software, particularly screen readers. Each country also had distinct media or software desirables that were fulfilled by social media connections. In Jordan, where Arabic text compatibility on screen readers is a major issue, social media serve as both a source of technological help and a source of new software, as this man described:

There are no problems as long as you are using English. Once you start using Arabic, the problems increase substantially. Sometimes, there are buttons that are not accessible. I need someone to click them for me. We use TTS (Text to Speech) that is installed on its own, and it has its own crack. This is the part that proves to be most problematic for Arabic. ... The current [screen reader] I am using is actually cracked; I installed it from the Internet. I got this link from one of my friends. We usually tell each other once we know if there is anything new. Respondent 14, Male, Jordan

The legacy of piracy in all three countries made online ‘crack’ sharing relatively uncontroversial. Respondents noted that cracked versions of JAWS were easily accessed through either networks or even CSOs (in India and Peru), primarily because of the prohibitive US\$1,000 price-tag of licensed JAWS. Respondents from all countries noted some variant of a ‘rotating pen drive’ with ‘cracks’ that got passed among friends seeking software.

Thus, as opposed to groups whose actions online impact the ways the discourse of disability is explicitly shaped, individual users have a very different set of motivations that drives and shapes their online activities. For organizations, social media are a means of representation, whereas for individuals, being online facilitates access to technical and social resources that existing structures make difficult to access.

Conclusion

The lack of significant distinction in respondents’ characterizations among access to AT, Internet, and social media specifically underlines ways in which the overall digital environment -rather than just one or another specific technology- has been transformative. Technologies intervene to facilitate certain types of independence in societies that are otherwise ill-equipped to provide an accessible social milieu. However, as we found with the use of the same technologies by the groups that represent people with disabilities, the nature of transformation can be very different.

Representational aspects of social media are complex, and the diversity of approaches in the three countries is indicative of the range of attitudes toward social inclusion. The nation–state, its institutions and culture, as well as those of the organizations representing people

with disabilities, play a crucial role in how online spaces are used by these groups. A widely accepted medicalized approach towards representing disability itself, and people with disabilities, as objects of charity was common in group representations in Jordan but not in Peru, where the approach was more interactive and focused on the vision-impaired community itself rather than sighted organizational supporters. In India, we found a mix of approaches depending on the groups themselves, their membership and their stance on disability issues.

From the individual's perspective, the creation of social capital was found to be particularly challenging without access to institutions, an important theme in all three countries. Social media, however, help individuals gain access to human networks that have immediate impacts such as access to technology and support, and less immediate longer-term impacts such as enabling individuals to maintain casual ties to acquaintances who can engineer economic and social connections. By providing the means to reach out to a larger community of people who can help in navigating assisted technologies, workplaces and public spaces, technology creates new forms of anonymity in help-seeking, thereby providing higher levels of independence to people in a world where social structures set limits on people with disabilities.

As likely with various other parts of the global South, the late access to AT for many of our respondents was an important deterrent to professional aspiration. Thus, rewiring assumptions about what kinds of careers would be within one's reach was important, and social media played a key role in spreading the word on possibilities. And yet, the same social media options could be used by organizations subscribing to old ideas about disability to reinforce the very stereotypes that individuals sought to overcome.

Indeed, many respondents reiterated their awareness of living in poor societies where they were among the privileged within the community of people with severe vision impairments, most of whom were excluded from access to technology and from various social and economic activities. For these respondents, the ability to be on social media often came with the responsibility to change social attitudes toward disability. The separation of the individual as a free agent on the social network from the individual acting as a representative of a community was frequently blurred. Social media stand at the vanguard of possibilities both on representation and on direct access to networks, but the voices of the people and organizations in the middle of it stand witness to the larger environment of contestation that evolves daily.

References

- Barker, C., & Murray, S. (2010). Disabling Postcolonialism: Global Disability Cultures and Democratic Criticism. *Journal of Literary & Cultural Disability Studies*, 4(3), 219-236.

- Bazna, M., & Hatab, T. (2005). Disability in the Qur'an: The Islamic Alternative to Defining, Viewing, and Relating to Disability. *Journal of Religion, Disability & Health*, 9(1), 5-27.
- Brady, E. (2013). *Investigating the Appropriateness of Social Network Question Asking as a Resource for Blind Users*. Proceedings of the 2013 Conference on Computer Supported Cooperative work.
- De Haan, D., Osborne, A., et al. (2014). Satire or Send-Up? Paddy Power and Blind Football: A Case for Managing Public Relations for Disability Sport. *Communication & Sport*, Jan 2014, 1-23
- Ellis, K. (2010). A Purposeful Rebuilding: YouTube, Representation, Accessibility and the Socio-Political Space of Disability. *Telecommunications Journal of Australia*, 60(2).
- Ghai, A. (2001). Marginalisation and Disability: Experiences from the Third World. In M. Priestley (ed.), *Disability and the Life Course: Global Perspectives* (pp. 26-37). Cambridge, UK: Cambridge University Press
- Ghai, A. (2002). Disabled Women: An Excluded Agenda of Indian Feminism. *Hypatia*, 17(3), 49-66.
- Goggin, G., & Newell, C. (2003). *Digital Disability: The Social Construction of Disability in New Media*. Lanham, MD: Rowman & Littlefield.
- Graham, L., Selipsky, L., et al. (2010). Understanding Poverty and Disability in Johannesburg. Report by Center for Social, Development in Africa (CSDA) and United Kingdom Department for International Development (DFID). Johannesburg, South Africa
- Granovetter, M. S. (1973). The strength of weak ties. *American Journal of Sociology*, 1973, 1360-1380.
- Groce, N., Kett, M., et al. (2011). Disability and Poverty: The Need for a More Nuanced Understanding of Implications for Development Policy and Practice. *Third World Quarterly*, 32(8), 1493-1513.
- Joinson, A. (2008). *Looking At, Looking Up or Keeping Up with People?: Motives and Use of Facebook*. Proceedings of the SIGCHI Conference on Human Factors in Computing Systems.
- Kriegel, L. (1987). The Cripple in Literature. In A. Gartner and T. Joe (eds.). *Images of the Disabled, Disabling Images* (pp. 31-46). Santa Barbara, CA: Praeger Publishers.
- Lee, D. (2012). (Where) Are Disabled Girls in Virtual Space? Representation of Disability and Gender in Google Images. *Critical Disability Discourse*, 4, 1-30.
- Lovejoy, K. (2012). Information, Community, and Action: How Nonprofit Organizations Use Social Media*. *Journal of Computer-Mediated Communication*, 17(3), 337-353.
- McCarthy, T. (2013). The 'Voice' Has It: Screen Reader Adoption and Switching Behavior Among Vision Impaired Persons in India. *Assistive Technology*, 25 (4), 222-229.
- Meekosha, H. (2006). What the Hell are You? An Intercategorical Analysis of Race, Ethnicity, Gender and Disability in the Australian Body Politic. *Scandinavian Journal of Disability Research*, 8(2-3), 161-176.

- Omansky G., Rosenblum, K. (2001). Bringing Disability into the Sociological Frame: A Comparison of Disability with Race, Sex, and Sexual Orientation Statuses. *Disability & Society*, 16(1), 5-19.
- Pal, J., Ammari, T., Mahalingam, R., Alfaro, A. M. H., & Lakshmanan, M. (2013). *Marginality, aspiration and accessibility in ICTD*. Proceedings of the Sixth International Conference on Information and Communication Technologies and Development.
- Parashar, D., & Devanathan, N. (2006). Still Not in Vogue: The Portrayal of Disability in Magazine Advertising. *Journal of Applied Rehabilitation Counseling*, 37(1), 13.
- Putnam, R. D. (2000). *Bowling Alone: The Collapse and Revival of American Community*. New York, London, Toronto, Sydney, New Delhi: Simon and Schuster.
- Seale, J. (2012) When Digital Capital is Not Enough: Reconsidering the Digital Lives of Disabled University Students. *Learning, Media and Technology*, 38(3), 256-269.
- Sentumbwe, N. (1995). Sighted Lovers and Blind Husbands: Experiences of Blind Women in Uganda. In: B. Ingstad, R. S. Whyte (eds.) *Disability and Culture, An Overview*, 159-173. Berkeley, Los Angeles, London: California University Press.
- Shakespeare, T. (1994). Cultural Representation of Disabled People: Dustbins for Disavowal? *Disability and Society*, 9(3), 283-299.
- Thomas, P. (2005). Mainstreaming Disability in Development: India Country Report. Disability Knowledge and Research Program. United Kingdom: Department for International Development (DFID).
- Turmusani, M. (2001). Disabled Women in Islam: Middle Eastern Perspective. *Journal of Religion, Disability & Health*, 5(2-3), 73-85.
- Waltz, M. (2005). Reading Case Studies of People with Autistic Spectrum Disorders: A Cultural Studies Approach to Issues of Disability Representation. *Disability & Society*, 20(4), 421-435.
- Wu, S., and Adamic, L. (2014). *Visually impaired users on an online social network*. In Proceedings of the 32nd Annual ACM Conference on Human Factors in Computing Systems, Pages 3133-3142