Assistive Technologies and Autonomy in a Cyborg World

Priyank Chandra
University of Michigan
105 S. State St, Ann Arbor, MI – 48109, USA
prch@umich.edu

Jasmine Jones
University of Michigan
105 S. State St, Ann Arbor, MI – 48109, USA
jazzij@umich.edu

ABSTRACT
This note discusses the use of cyborg theory to study assistive technology (AT) use by people with visual impairment (VI) in development contexts. We argue that the deep intimate interconnections that people form with their AT, while allowing them to become cyborgs, also become the means by which they can be regulated and controlled. This is a concern for ICTD, which strives to consider the instrumental outcomes of technology implementation as it is interwoven throughout people's lives. Applying Lessig's model of regulation to a cyborg body, we discuss the implications for protecting autonomy in AT use by people with visual impairment.

Author Keywords
Assistive Technology; Cyborg

ACM Classification Keywords
K.4.1: Public Policy Issues; K.4.2: Social Issues

INTRODUCTION

Close to 314 million people worldwide have visual impairment (VI) with 90% of them living in low-income settings [24]. People with disabilities have historically remained in a state of dependency through a range of forces - economic, political, and professional [17]. Recent times have seen a move to approach disability as a socio-political problem rather than just a medical one through critically analyzing what it means to be 'normal' and 'able-bodied' [14]. This has been accompanied by demands to restructure the world to reduce dependency and break down barriers that restrict equal accessibility [4]. Assistive technologies (ATs) are an integral part of this movement, consisting of the specially-designed devices that help the disabled overcome these barriers and help bridge the gap between their needs and what is offered by the existing social architecture [13].

Appropriate and well-designed ATs help increase autonomy and social inclusion for people with disabilities. They have the potential to improve quality of life by reducing the environmental and social barriers that they face. However, their success is highly contingent on structural and institutional factors. Access to ATs is limited, especially in low- and middle-income countries where only an estimated 5 - 15% of the people needing ATs have access to them [24]. Further, even those with access to ATs still find themselves marginalized across the world. This paper takes the perspective of cyborg theory to argue that the marginalization of people using ATs is not simply an unfortunate economic reality, but is influenced by how integral technology is to their lives and how external forces regulate both the individual and the technology.

For people with VI, independence in society is contingent on their connectivity with ATs. Over the last few decades, there has been a growing interest in how the ontology of body and selfhood is altered by the deep relationships that humans have with technology [8, 11]. The human body, made malleable by technologies, represents a new paradigm of cyborgs that are, as Donna Haraway [11] writes, "a hybrid creature, composed of organism and machine". ATs interconnected with human bodies allow the creation of cyborg bodies that impact an individual's identity through creating new interactions, abilities to connect and relate to people, and means of aspiring. However, our note argues that these intimate relationships between users and their ATs can become another avenue for individuals to be regulated.

THE CYBORG BODY AND ICTD

The concept of cyborgs, short for cybernetic organism, has its origins in self-regulating human-machine systems, where technology was a means to supplement the body, allowing the mind to remain human [10]. However, it has since been used as a metaphor that allows traditional boundaries of identity to be blurred [11]. Cyborgs cover a wide spectrum of human-technology couplings: restorative, normalizing, enhancing, and reconfiguring [8]. In a world where everyone is part human, part machine, boundary figures such as people with disabilities using ATs (among other groups) become the norm rather than the exception [16].

Here, we define a cyborg as a human body that incorporates technology to extend itself to better adapt to the environment. The idea of cyborgs is certainly not new to ICT and Development (ICTD) literature – much of the work in ICTD deals with how ICTs extend the abilities of marginalized individuals and allow them to craft new

ICTD '15, May 15 - 18, 2015, Singapore, Singapore

ACM 978-1-4503-3163-0/15/05 $15.00
http://dx.doi.org/10.1145/2737856.2737905

identities for themselves [2]. However, explicitly using cyborg theory helps us highlight how these human-machine hybrid identities are enmeshed within social and material forces.

THE CYBORG BODY, DISABILITY AND ASSISTIVE TECHNOLOGIES

ATs are a means by which people with disabilities can reconfigure their identity and relation to society, by both extending the physical body through material devices and extending the individual's subjectivities through information and communication technologies [5]. With advances and increasing ubiquity of digital technology, the boundaries between body and ATs have increasingly become blurred over the last few decades. The tightly-knit relationship between technology and humans is evidenced in research on ATs, which show how an individual's culturally defined identity is shaped by them being an AT user [1, 21].

Cyborg theory allows us to look at the structural, economic and institutional factors that contribute to the creation of human-machine hybrids, along with the forces that curtail their autonomy. In taking this practical approach, we answer criticisms of cyborg theory in its application to disability studies that have argued that cyborgs as a liberating political identity is meaningless when the vast majority of people with disabilities are still marginalized [20].

Through analyzing the forces that regulate human-machine coupling, we can see how even a cyborg body might become "disabled", or, in other words, how an individual with access to technology can still be "disabled" in society. We argue that humans are indeed becoming cyborgs through their relationship with technology, but because of these relationships, technology becomes yet another avenue to control the individual.

First, we present a case study that reinforces the assertion that assistive devices are not simply a tool, but are a critical extension of the body and the self for people with visual impairments. Following this illustration, we elaborate on the ways that people with disabilities can still be marginalized by sociotechnical forces despite the empowering potential of ATs. Further, we demonstrate the power of the cyborg lens in our discussion of how ATs can betray people with disabilities when it becomes an intimate means to control and disempower them.

DATA

Empirical support for this argument is drawn from secondary analysis of data from two separate, previously conducted qualitative studies. The original purpose of these studies was to investigate the nature of AT use by the visually impaired in development contexts. Upon discussion of the data sets by the co-authors, a common theme of technology and identity was identified. The data were revisited using this theme to understand it from a cyborgian perspective.

The first study, conducted from 2012-2013 in Bangalore, India focused on AT and workplace experiences of VI adults. Data was collected through interviews from 101 participants, one-third of them women. The second study, conducted in 2013 in Sierra Leone assesses the level of access, usage, and impact of ATs. Data was collected through surveys administered to 33 respondents, fourteen of which were women. Data from the first study was used to develop the theoretical framing used in this paper. The second study provides an illustrative case on which to apply the cyborg lens.

Analysis

In a study by Pal et al. [18], the significance of AT in the lives of people with VI was directly addressed. Their findings of AT use by visually impaired individuals in India, Jordan, and Peru showed that, in terms of aspirations and self-conception, technology was able to radically transform people's lives, supporting the reconfigurist notion of technology's impact on marginality. People reported access to basic educational and social activities, such as reading a book that they did not have access to previously. This access, although only a peripheral form of social inclusion, had a radical effect on participants' self-image, especially due to its impact on their possibilities for independent living.

The Pal et al. [18] study showed that AT, through its empowering effect, was perceived as part of participants' identities. Findings from the survey conducted in Sierra Leone corroborate this perception, and provide evidence for the integral nature of technology in the lives of people who are visually impaired.

In Sierra Leone, respondents had extremely limited access and experience with typical IT assistive technologies, such as screen readers and mobile text-to-speech software. Feature phones were their primary personal IT, with only two respondents reporting experience using a computer outside of a classroom setting. Despite the limitations they faced due to a largely inaccessible interface, they still regarded mobile phones as a critical tool in their lives, connecting them to the world and to opportunity.

"I so much got used to it, that when I get my phone away from me, even charging, I feel uncomfortable…. Sometimes you don't even want to remember that the phone is not near you. Everyday activity you want to go out, and communicate your way. I sleep with my phone. I can go [only]one day without it."-R16

Without assistive software on their phones, VI people were only able to use the calling feature on their phone. To send or receive text messages, check missed calls, or access phone based financial services they requested help from a sighted friend or relative. Even without all the features normally available, the connectivity and social participation enabled by the mobile phone made it an invaluable asset.

With a cyborg lens, we see that the phone was more than a valuable tool. It was a critical component of VI respondents' way of relating to the world. It was a mediator for

communication, a mobility aid, and a means to live everyday life "[their] way." When asked how long they could go without a phone, over half of respondents adamantly replied they could not "cope" any length of time without a phone.

"It has a psychological effect. I feel I'm not part of the world [without my phone]. I get frustrated because I feel alone without a mobile phone." -R29

The ability to communicate over a distance was a life changing ability gained using a mobile phone. Unlike a sighted person, a visually impaired person in Sierra Leone could rarely venture out of their home unaccompanied, due to the inaccessibility of the infrastructure and personal safety concerns. Only two respondents regularly used a white cane to travel independently, with the majority using sighted guides when they wanted to travel from place to place due to accessibility and safety concerns. Depending solely on the availability and willingness of sighted guides to enable them to see and talk to friends and family created a situation where VI respondents felt isolated and lonely. R30 described the loss of his phone as feeling "lost" himself, having few alternatives to bridge the social distance between him, his family, and his friends.

My whole life is built off my phone. –R19

I would have difficulties with mobility, earning income, I cannot communicate. I would feel outcast. –R31

The mobile phone for respondents was an appropriated AT. Although not specifically designed to help them overcome barriers to participation in society, they leveraged its features to their benefit and based the expectations of their daily lives around its availability. This augmentation was not easily reversed. Even the time it took to charge the phone was a painful period separation of a technology that had become fully incorporate in their lives.

By applying a cyborg lens to understanding this brief example, we see that mobile phones were not simply an invaluable tool, nor were they mere substitutions for an ability that respondents lacked or a service provided by others. The mobile phone in this context was an augmentation of the self, its features becoming part of the individual's abilities and its displacement felt as an intimate loss. Even with limited accessible features, mobile phones had been absorbed into VI people's way of relating to the world, and provided an infrastructure through which they were able to participate in previously exclusive social contexts.

ASSISTIVE TECHNOLOGY, CYBORGS AND REGULATION

Classifying the intimate relationships that people with VI form with their ATs as 'cyborgian' goes beyond just semantics. It is a powerful reclassification that focuses our attention on how the freedoms that people enjoy are highly dependent on the nature of technologies that they are coupled to. With ATs augmenting an individual and thus becoming an integral part of their identity, external forces that control the technology directly influence the autonomy of the cyborg [3].

Lessig [15] describes four modalities that regulate the lives of individuals - the architecture, the law, social norms, and the market. When looked at from the perspective of cyborgs, these constraints simultaneously regulate the biological body and the technologies they have access to. The architecture is the sum total of the technical and physical structures that enable and constrain the use of ATs. While technical constraints were part of the architecture in the regulatory model defined by Lessig, in a cyborg world the technology can no longer be treated solely as an external regulatory actor. The regulation of the technological aspect is crucial in understanding how individuals, as cyborgs, are constrained indirectly through the technology. And while this is true for all technologies, it is particularly crucial when analyzing ATs given the transformative power that they are purported to have. In a cyborg world, the social construction of disability intersects with the politics of technology – the forces that shape technologies also shape disability.

Markets regulate the supply for ATs, while playing a crucial role in shaping the nature of new technologies. The relatively high costs of obtaining an AT, as well as its limited supply, affect the ability of individuals to obtain and use them [6]. Further, there is a distinct lack of awareness by designers of the diversity of potential users and their needs [9]. Social norms influence how those using ATs are perceived by society, and whether people with VI using ATs are socially accepted as equals, even when they are functionally equivalent [23]. Through laws, the government is able to mandate the nature of ATs that various institutions within a society are legally obligated to provide. In Sierra Leone, for example, to operationalize the ratification of the UN CRPD (Convention on the Rights of People with Disabilities), the country adopted the Disability Act to legislate, among other things, the provision of assistive devices, equipment, and services to people with disabilities necessary to ensure their "right to a barrier free environment" [19].

Policy-makers and designers have to be aware that ATs are not 'enabling' in themselves; their potential is conditional on how the cyborg body is regulated by formal and informal institutions. The adoption, use and impact of any AT will ultimately not just be a function of the technology or the individual's needs, but dependent on a range of socio-cultural, technical and legal constraints that regulate both the technology as well as access to these technical artifacts. With governments and corporations controlling and shaping ATs, the cyborg body is not going to be autonomous until it is included in the process of design and policy-making.

DISCUSSION

In a cyborg world, the underlying theme is that technology radically changes the identity of individuals – both their self-identity and how society looks at them. Ideally, ATs should

allow people with VI to transcend their socially constructed 'disabilities' and create fluid identities that are subject to a combination of their bodies and the assistive technology they choose to use. But cyborgs in society are restricted in three important ways that policy-makers need to be cognizant about – 1) in the limited choices of AT they have access to, 2) the nature of ATs they do obtain, and 3) how these ATs are regulated.

For example, a closed, proprietary IT system in contrast to free open source allows corporations to regulate and control the system and all technologies that depend on it. Here, the nature of the code ties an individual to a set of existing institutions, while the licensing agreements regulate whether a technology truly belongs to the cyborg. Take for instance, when AT has a technical breakdown or requires an upgrade--in a proprietary model, the individual is forced to surrender to the demands and conditions (such as terms of use and warranty) of the corporation to service and restore it. These bring in questions of true autonomy, and if the possibility spaces of the cyborg are consequently limited by state and corporation control invading the technology that make it up.

Amartya Sen [22] talked about how the expansion of freedom is both the primary end and the principal means of development. Expansion of freedom in a cyborgian sense would mean giving individuals greater control of the technologies that constitute their cyborgs bodies. People with disabilities, like many others, are already redefining themselves through the technology they access and one important means to ending their marginalization would be expanding the control they have over their own cyborg bodies.

From an ICTD perspective, looking at technology adoption through a cyborg lens allows us to acknowledge the deep intimate interconnections that humans form with technology. This indeed is a theme for much ICTD work, which while considering the instrumental outcomes of technology implementations, is deeply interested in how technologies append our abilities and reinvent people and societies. The ongoing challenge is to address the critical inequalities of technology divides through more inclusive development models [12]. In a cyborg world, inclusion is not simply about provision of a technology; it is about enabling empowerment and self-realization of marginalized groups through autonomy, opportunity, and independence afforded by ATs.

REFERENCES

[1] Apelmo, E. Falling in love with a wheelchair: enabling/disabling technologies. Sport in Society 15, 3 (2012), 399 – 408.

[2] Buskens, I. 2010. Agency and Reflexivity in ICT4D Research: Questioning Women's Options, Poverty, and Human Development. *Information Technologies & International Development* 6.SE (2010): pp-19.

[3] Chopra, S. and Dexter, S. 2007. Free software and the political philosophy of the cyborg world. *ACM SIGCAS Computers and Society*. 37, 2 (2007), 41–52.

[4] Coombs, N. 1990. Disability and technology: A historical and social perspective. ERIC Clearinghouse.

[5] Cromby, J. and Standen, P. 1999. Cyborgs and stigma: technology, disability, subjectivity. *Cyberpsychology*. (1999), 95–112.

[6] Eide, A.H. and Ødegård, T. 2009. Assistive Technology in Low-Income Countries. *Disability & International Development*. Springer US. 149–160.

[7] Elisabet Apelmo 2012. Falling in love with a wheelchair: enabling/disabling technologies. *Sport in Society*. 15, 3 (Apr. 2012), 399 – 408.

[8] Gray, C.H. ed. 1995. *The Cyborg Handbook*. Routledge.

[9] Gregor, P. et al. 2005. Disability and Technology: Building Barriers or Creating Opportunities? *Advances in Computers*. Elsevier. 283–346.

[10] Hacking, I. 1998. Canguilhem amid the cyborgs. *Economy and Society*. 27, 2-3 (May 1998), 202–216.

[11] Haraway, D. 1985. A manifesto for cyborgs: science, technology and socialist feminism in the 1980's. *Socialist Review*. 80 (1985), 65 – 107.

[12] Heeks, R. 2014. ICT4D 2016: New Priorities for ICT4D Policy, Practice and WSIS in a Post-2015 World. (2014).

[13] Hersh, M.A. and Johnson, M.A. eds. 2008. *Assistive Technology for Visually Impaired and Blind People*. Springer London.

[14] Kanter, A.S. 2010. Law: What's Disability Studies Got to Do With It or an Introduction to Disability Legal Studies, The. *Colum. Hum. Rts. L. Rev.* 42, (2010), 403.

[15] Lessig, L. 2006. *Code*. Basic Books.

[16] Moser, I. 2000. AGAINST NORMALISATION: Subverting Norms of Ability and Disability. *Science as Culture*. 9, 2 (Jun. 2000), 201–240.

[17] Oliver, M. 1989. Disability and dependency: a creation of industrial societies. *Disability and dependency*. 6-22.

[18] Pal, J. et al. 2013. Marginality, aspiration and accessibility in ICTD. (2013), 68–78.

[19] Persons with Disabilities Act. Sierra Leone. 2011.

[20] Reeve, D. et al. 2012. Cyborgs, Cripples and iCrip: Reflections on the Contribution of Haraway to Disability Studies. *Disability and Social Theory: New Developments and Directions*. (2012), 91–111.

[21] Ripat, J. and Woodgate, R. 2011. The intersection of culture, disability and assistive technology. *Disability & Rehabilitation: Assistive Technology*. 6, 2 (Mar. 2011), 87–96.

[22] Sen, A. 1999. *Development as freedom*. Oxford University Press.

[23] Shinohara, K. and Wobbrock, J.O. 2011. In the shadow of misperception: assistive technology use and social interactions. (2011), 705–714.

[24] World Health Organization and World Bank 2011. *World report on disability*. World Health Organization.