The Role of HCI in the Construction of Disability

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Assistive technology research and development community deals with a phenomenon that goes beyond medical concerns. For many years, international human-rights organizations, disabled activists, and disability studies community, have proposed alternative discourses on disability that, from different perspectives, expand the understanding on the phenomenon, potentially impacting on HCI praxis. However, assistive technology literature is still deeply rooted in the much maligned medical model of disability. Following this model have practical, ethical, and political implications, for it potentially obscures the underlying social inequity. The threefold objective of this paper is to raise awareness within the HCI community about the existence of different discourses on disability, to call into question the idea of 'neutral praxis', and to suggest that interpreting and understanding the social forces underneath HCI praxis might provide more appropriate and useful solutions.

Assistive technology. Disability. Ideology.

1. INTRODUCTION

Slowly, the assistive technology research and development community is adopting the alternative, and less oppressive, models of disability proposed by international human-rights organizations, disabled activists across the world, and the disability studies community, aimed to foster, not without fundamental disagreements in approach, social inclusion, human diversity, and the equalization of opportunities for disabled people.

The World Health Organization (WHO), due to the pressure of disability organizations to renew the previous International Classification of Impairments, Disability and Handicap (ICIDH), published in 1980, developed the International Classification of Functioning Disability and Health (ICF) in replace of the former. The new classification manual, endorsed by WHO member states in 2001, is intended to shift the focus from disease to health and functioning, acknowledging that "every human being can experience a decrement in health and thereby experience some disability" (WHO, 2002). In particular, it proposes a new model of disability so-called the 'biopsychosocial model', in replacement of the prevalent individual medical model of disability, that sees disability as a complex phenomenon caused by different interacting factors, including the environment, going beyond the notion of impairment as the only cause. ICF provides a classification system aimed to allow for consistent and internationally comparable data collection. The new nomenclature substitutes the terms 'impairment', and 'handicap', for considering them confusing and misleading.

However, a quick review of assistive technology literature shows that not only the WHO's eleven-year-old model had little penetration in the HCI discourse on disability, but that the previous discourse survives and keeps reproducing. Three examples give account of this issue:

Example 1. Performing a full text search in the three major international conferences on the topic, ASSETS, ICCHP, and UAHCI[1], reveals that the term 'ICF' appears in[2]:

- No results in ASSETS, out of a total of 433 published papers;
- 11 out of 718 papers in UAHCI (1.5%);

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[1] ASSETS is the ACM's conference on computers and accessibility, published by ACM (Association for Computing Machinery); ICCHP is the International Conference on Computers Helping People, published by Springer-Verlag; UAHCI is the International Conference on Universal Access in Human-Computer Interaction, published by Springer-Verlag.
[2] The search included articles from 2002 up to 2012.

- 23 out of 916 papers in ICCHP (2.5%).

Example 2. ICCHP's papers relating to ICF have received little attention. Notably, a paper published in 2006 by Billi et al, entitled "A Classification, Based on ICF, for Modelling Human Computer Interaction" (Billi, 2006) was cited only once[3].

Example 3. Chapter 42 of the reference book The Human-Computer Interaction Handbook, entitled "Physical Disabilities and Computing Technologies: An Analysis of Impairments" (Sears, 2008), is based on the WHO's obsolete and much maligned ICIDH[4]. Despite this work contributes a comprehensive description of "the more common diseases, disorders, and injuries associated with [physical impairments]", which might provide an entry point for HCI researchers understanding the medical issues that contributes to the production of disability, its discourse is based in the normal-abnormal dichotomy that has arguably been shown to be inefficient and potentially harmful (Oliver, 1994). This work had an important impact on HCI literature, with more than seventy citations, including conference papers, journal articles, and books.

Such an exiguous reference to the ICF in assistive technology literature raises several practical questions that have powerful ethical and political implications: How are assistive technology researchers and professionals classifying disability? How are we (I include myself in the assistive technology community) communicating our results to other colleagues inside and outside the discipline? How are we comparing different solutions, possibly proposed by different researchers in different contexts, to the same problem? How are we measuring the social impact of our praxis? Finally, ICF warns about the flaws of the medical model in understanding the real problem dimension, potentially narrowing the solution scope. Thus, what kinds of problems are we finding, and what kinds of solutions are we providing?

Neither has assistive technology literature reacted sufficiently to the attempts of the thirty-year-old disability studies community to "define the rhetoric, language, methods, and purpose of academic work related to personal and social experience of disability" (Mankoff, 2010), promoting a more comprehensive 'social model' of disability.

In the following sections I will try to expose that neutrality is an illusion, that HCI praxis is inherently impregnated with ideology, and that HCI researchers and professionals serve, being aware or not, as vectors that reproduce a particular world-view with its practical, ethical, and political consequences. In particular, as interaction between people and computers has turned into a large-scale phenomenon, to the point that it mediates social relationships, HCI praxis should understand not only the user, but also the total setting of the solution's application, including —and questioning— its fundamentals. As Agre points out, "attempts to improve things may alleviate some symptoms but they may also obscure the systemic disorder underneath" (Agre, 1995). Going further, and consistently with Welsh's *symbols of separateness* (Welsh, 1995), the semantics of every product or service we develop embeds two meanings: the meaning of what the user can and cannot do within a particular application context (what Norman calls *affordances*, adopting and adapting Gibson's definition), and the meaning of what is the *normal* user to the designer's view. If not well conceptualized, the product or service, through its second meaning, could become a tool of oppression.

2. DISCOURSES ON DISABILITY

The model of disability, i.e. what we understand when we think about disability, conditions our praxis. There are many discourses on disability. Each discourse is rooted in a particular world view. When we develop as researchers and professionals, we are —being aware or not— framed in a particular set of preconceptions, ideas, beliefs, thoughts, and intuitions, that we inherit from our culture (Ricoeur, 1986). From a political point of view, choosing —following— one particular discourse, and not other, means reproducing a particular ideology. From the point of view of professional praxis, it means conditioning the methods, strategies, approaches, technologies, and even the ability to provide adequate solutions to a given problem.

For example, if we understand disability as a deficit in the body structure or function, as it is broadly extended in the western society, our praxis would be biased toward providing *medicalized* solutions. This emphasis on the body condition enables certain classes of solutions, which typically involves providing individualistic treatments in one-size-fits-all state or private agencies. Moreover, a discourse of this kind, that reduces the disability phenomenon to people *carrying* disability, "reinforces the view that humans are flexible and adaptable while physical and social environments are not", and also "downplays the role of legislation and policy reforms to address the various economic and social disadvantages experienced by people" labelled

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'disabled'" (Barnes, 2011). Thus, the discourse may succeed on partially solving the problem, instead of addressing the wider, more complex problem that involves the whole society. Alternative discourses may allow for discovering different problems, and finding alternative broader and long-termed solutions.

WHO's current biopsychosocial model of disability, condensed in the ICF manual, agrees that the medical model does not tackle the root causes of the disability phenomenon, and proposes that disability is a "complex interaction between the health condition of the individual and the contextual factors of the environment as well as personal factors" (CDC, 2012). The model takes into account environmental factors (called contextual factors) that could potentially diminish people's functions, regardless their body condition. For example, an ill-designed university cafeteria with poor acoustic can dramatically disrupt conversation, and interfere with informal communication, affecting people's participation. It is possible, at least in theory, to use the ICF manual to assess the impact of the cafeteria's building design on its users —that are somehow disabled by the environment—, and to define policies for addressing the problem —for example, hiring an acoustical consultant. ICF also provides a classification system that allows for identifying the kinds and levels of disability, and comparing data in a consistent and internationally comparable manner (WHO, 2002).

However, ICF has been subject to criticism by some disability activists and organizations, including Colin Barnes, one of the main contributors to the disability studies discipline. According to Barnes, the ICF: "reaffirms the western scientific medical approach as the basis for classifying, measuring and treating 'biophysiological' conditions"; does little to facilitate researchers and policy makers to quantify the contextual (environmental and personal) factors affecting people's participation; reaffirms the conception of *normality*; assumes that *normality* is a concept that remains invariable within and across different cultures; and does not provide a useful framework to develop policies (Barnes, 2011).

Dissenting with the medical and the biopsychosocial models, that either reproduce or do not challenge the hegemonic discourse on disability, and that take *normality* as a natural fact, the social model of disability focuses on the empowerment of disabled people. The social model not only recognizes the importance of individually based interventions, including medical interventions, habilitation and rehabilitation therapies, and educational or employment based interventions. Moreover, it attempts to "shift attention away from the functional limitations of individuals onto the problems caused by disabling environments, barriers and cultures" (Barnes, 2011).

Although disability studies literature has addressed issues related to assistive technology, embracing Universal Design as the best approach to develop technology, the opposite does not always happens (Mankoff, 2010). That begs the question, then, of which discourse on disability are we —HCI researchers and professionals— following, and, consequently which methodologies are we applying, and which framework are we using to evaluate the effectiveness of such methodologies.

3. IDEOLOGY BEHIND NEUTRALITY

There are not neutral discourses. Behind the image of neutrality there are particular conceptions of reality deeply rooted in a particular ideology. Thus, it is our responsibility, as researchers and professionals working on disability, to understand and to call into question the underlying discourse that supports our praxis.

It is not possible to define praxis only in terms of the methodologies, techniques, and tools we apply within a community, for "we cannot work without bringing in our traditions and our symbolic interpretation of the world" (Ricoeur, 1986). Moreover, the underlying institutional framework of society —including physical, and cultural constructions— acts as a force that determines and solidifies the cartography of the 'problems space', thus limiting the scope of our solutions. This happens in part because the institutional framework is itself an attempted solution to overcome a particular problem, and praxis is constructed with and over that preconceived solution.

For example, let us suppose that we are engaged in a project aimed to develop technology for an institution for children with physical disability. If we do not call into question the very fundamentals of the institution, we probably would provide individual solutions to, for example, address accessibility, or stimulate motor skills. Conversely, if we realize that we are working at a one-size-fits-all institution receiving children from many remote communities, we could provide a more comprehensive solution that promotes and engages communication among children from the different communities, and among their parents.

Thus, physical and cultural constructions form part of the exclusion process, allowing and denying participation to people with disability (Barnes, 2011). Design in its many disciplines, specially interaction design, industrial design, environmental

design, and architectural design, plays a fundamental role in the production of disability. Poorly designed software and physical products, services, and environments, disable people —not only people with impairments— at various stages in the life course (Barnes, 2011).

Having, therefore, a nuanced understanding of the forces underneath HCI praxis, and understanding, but not only, the user needs within the community, have practical implications in our ability to provide solutions.

On the other hand, as HCI research —being aware or not— is stick to a particular world view, it cannot be considered neutral, for the purpose of language is more than communication. Language "is also about politics, domination, and control" (Oliver, 1994). It is a collective and organically developing phenomenon. Consequently, any work related to disability, including books, journal articles, conference papers, scientific or technical reports, dissertations, et cetera, explicitly or implicitly — often more implicitly than explicitly— conveys and reproduces a particular world-view. In the case of assistive technology literature, this view has typically been aligned with the dominant discourse on disability. Because of the impossibility of achieving a neutral discourse, it is important, useful, and fair, to state explicitly which discourse underlies the research, or, at the very least, to be aware of the research's direct and indirect effects on society.

Every paper is a political statement that may have social implications. Perhaps in other disciplines this issue is harmless, but HCI praxis involves human research. As Mike Olivier suggests, an appropriate discourse provides the basis to develop appropriate welfare provision and professional practice (Oliver, 1994).

4. CONCLUSION

I have tried to expose that praxis, including HCI praxis, is always rooted in a particular ideology. As Paul Ricoeur remarks in Lectures on Ideology and Utopia, "praxis incorporates an ideological layer; this layer may become distorted, but it is a component of praxis itself" (Ricoeur, 1986). As a discipline performing human research and providing solutions to people, it is critical for HCI researchers and professionals to understand the social implications of HCI praxis, and it is not possible to do this sincerely without agreeing that there are not neutral discourses.

Assistive technology researchers and developers deal with a complex phenomenon that is more than a biological matter. Disability is an issue that reflects profound social asymmetries, unbalanced power relations, and engenders many conflicting interests. Thus, HCI and assistive technology literature should take a critical look at the prevailing discourses on disability, like the medical model, and consider alternative ones, like the social model.

Once being aware of this need, adopting a particular disability model would allow HCI research on disability to standardize methodologies, improve communication within and across disciplines, assess the praxis' social impact, and provide better solutions.

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