Assistive Technology Research and Disability Studies in the Global South: the Need for Synergy

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INTRODUCTION

In the nine years of ASSETS conferences after Mankoff [12] there is less than a handful of papers [3, 7, 2, 4] that have intersections with disability studies scholarship. A scan of the titles and abstract of the past three years of CHI papers revealed that out of the more than 2000 papers, the number of papers that primarily build on Disability Studies is near zero. Alarming as this number is, it is even more concerting to note that, no mention is made of the emerging field of Disability Studies in the Global South. At the same time, there has been a large contribution of critical scholars on issues around design and socio-technical issues who have been an active and integral part of all CHI venues in recent years. Scholars of disability studies in the global south, many of who have been at the vanguard of disability-related scholarship and activism in the past few decades, have not been part of the discourse on assistive technology with a few emerging exceptions. For instance, a recent national conference[1] on assistive technology had a session on the technology solutions for people with disabilities in the global south. In this paper we would like to highlight the critical need to include voices from disability studies in the Global south in any discourse on Assistive technology design and development. We present the following reasons for this importance:

1) The majority of the global population of people with disabilities live in the global south. And it is well established that people with disabilities around the world are among the most marginalized populations, including in the global south. 2) The lived realities of people with disabilities (PwDs)in the global south are very different from those of the people with disabilities in the global north where the statutory, legal, financial, and infrastructure capacities are well developed and hence the quality of life of PwDs is at a minimum on an upward trajectory. In the global south, by definition, there is a serious deficit in these capacities, including the capacity of

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[1]Empower 2019 http://assistech.iitd.ernet.in/empower2019/index.php

the PwDs to absorb any available benefits. 3) Assistive technology work in the global north works on the premise that independence and access that is equal to the mainstream population is the desired end goal of the people with disabilities. However, this premise is being questioned by scholars in the global south; in the foreseeable future, PwDs primarily depend on their immediate family, and proximal social groupings for their everyday lives and not on government programs or public resources, even if legally mandated. Thus, the design of assistive technology solutions for these populations have to be rethought from the bottom up, taking the social context and the existing networks of support around PwDs.

We provide three streams of thought to seed further conversations on this intersection. 1) An overview of literature of the disability studies in the global south, especially those with any intersections on technology 2) A personal narrative of two of the authors of their experience of being women and disabled and growing up in two diverse regions of India, one from Delhi, the capital city and the other from a rural neighborhood of Bangalore. and, 3) A new methodology that we call Ludic Design for Accessibility[17] which has been informed and influenced by the above.

DISABILITY STUDIES IN THE GLOBAL SOUTH

The following are some of the key references that highlight the distinction between disability as viewed in the global north and the perspective in the Global South. Clearly this is far from a systematic survey of all the relevant literature. We simply quote some key ideas from each of these references without providing a detailed commentary.

- "North-South terminology, then, like core-periphery, arose from an allegorical application of categories to name patterns of wealth, privilege, and development across broad regions. The term Global South functions as more than a metaphor for underdevelopment. It references an entire history of colonialism, neo-imperialism, and differential economic and social change through which large inequalities in living standards, life expectancy, and access to resources are maintained."[6]

- Southern Bodies and disability: rethinking concepts. "One reason is that a universal form of knowledge cannot be based on the experience of a privileged minority alone... The great majority of disabled people–80% in one estimate– live in the global South. A second reason is that an intellectual

project that cuts itself off form most of the wold's cultures, and many of its most creative intellectuals, radically impoverishes itself. This is not a good base for confronting the daunting problems of world society today"... " As a field of knowledge, disability studies currently has the same global North focus as other fields of human sciences." "the colonised and postcolonial world has intellectual resources. It has ideas principles, research agendas, art forms and religions that can inform struggles to overcome marginality, prevent damage, and make the voices of disabled groups heard."[5]

- Human rights and the Global South: the case of disability

  "northern discourses of disability rights have strongly influenced the UNCRPD. We argue that many of the everyday experiences of disabled people in the global South lie outside the reach of human rights instruments. So we ask what, if anything, can these instruments contribute to the struggle for disability justice in the South? While Northern discourses promote an examination of disabled bodies in social dynamics, we argue that the politics of impairment in the global South must understand social dynamics in bodies."[13]

- '<details about number of disabled people in India, distribution among the sates, male/female etc>. My submission is that quantitative data is a product of conjecture because interpretation of disability is culture-sensitive. Whether any human being marks himself/herself as disabled is interpreted in terms of attitudes and beliefs towards disabled person in a given cultural understanding. Thus, disability is deeply embedded in the scared texts, mythology, cinema, scriptures, folklore (stories and songs), proverbs, poems and riddles." [9]

- " Whether disabled people are included in development or not, the reality is that the poorest, including disabled people, continue to survive on their own accord, using their own means, and it is these means and strengths that we need to build upon and ensure that we do not trample upon or destroy discursively or materially. Openly listening and learning from disabled people, their families and communities, and prioritizing their voices is critical starting point, even when these voices may go against our own subjectivities, definitions and approaches to disability and development."[10]

- "There has been little parity in the exchange of ideas between countries of the South and the North; rather the flow of information has been unidirectional, from the North to the South. Thus existing debates around inclusive education in the South, we would argue, have ignored important contextual and cultural specificity, and have largely failed to engage with the strengths and tensions within existing educational and broader socio-cultural systems."[16]

It is interesting to note that only a few of the publications in the disability and global south area focus on technology in general. For instance, [18] explores the lack of accessibility to digital technology pointing out that every new digital artifact enhances the sense of exclusion among the disabled populations in the global South, with the title "Cool stuff for other people?" capturing the essence.

In [7] the authors "argue that the underlying philosophical position implied in this approach can be seen as reductionist as the disabled experience is arguably richer and often more complex as can be projected from the functional limitations of people. Thinkers and activists in Disability Studies have conceptualised disability in various ways and more recently, critical realism was proposed as a philosophical position through which the many different facets of the disabled experience could be incorporated."

Roy et al. [15] present a "series of snapshots, each identifying gaps in scholarship, media attention and a critical gaze in global disability studies.' with respect to digital and network technologies.

Pal et al. [11] "examine the gap between the policy promise of technological accessibility and existing social and economic infrastructure. We examine the idea of accessibility infrastructure and specifically focus on its social components through two factors — stigma related to disability, and the community around technology users — both of which emerge as important factors in enabling or excluding AT use."

We could find no work that discusses the design of assistive technologies specifically taking into account the context for the Global South.

LIVED EXPERIENCES OF DISABILITY
In this section we give brief first person vignettes of the lives of the first two authors.

Vidhya Yella Reddy
Vidhya is currently a Research Fellow at Microsoft Research and also the co-founder of the non-profit Vision Empower Trust that aims to enhance STEM opportunities for children who are blind or low vision (BLV). Her current research projects include digital skilling of children who are BLV in schools for the blind in India and a qualitative study of adults who are BLV and their journey from childhood with a focus on their technology interactions and education. Excerpts from her autobiographical account(in preparation).

Birth and blindness:

My parents lived in rural Bangalore with their extended family. Since the time they were expecting me, there was nothing but celebration at home, as they had waited for a little more than 6 long years to hold their first child in their arms. The day I was born turned out to be a nightmare for my family, as I was born 2 months prior the expected date and weighed only 1.1 Kg. I couldn't breathe normally and did not have the necessary strength required for functioning and I had to be rushed to the incubator if I had to survive. This meant that my parents had to weight 3 additional months to hold me for the first time!

In a few days of bringing me home, my mother noticed that I had a glass like additional growth in both my eyes and took me to the family doctor. The doctor referred my parents to another doctor who assured that I will be able to see and referred us to

another doctor. Visiting hospitals became a daily affair for my family not only as I weighed lesser than the normal, but also as my blindness symptoms were noticeable as the days passed. This continued for the first 4 years till one of the doctors in a reputed hospital in south India operated one of my eye, and informed my parents that I will never be able to see unless a miracle occurred, or Science and technology advances to a point that all blind people will be able to see. The doctor also informed my parents that further efforts in trying to restore my eyesight in different hospitals was futile as my condition did not have the potential to be treated anywhere in the world, instead urged my parents to give me the best education as they had already named me Vidhya which means knowledge or learning in Sanskrit and as I was born on world literacy day! This visit not only caused a great distress to the family for years to come, but also gave a sense of direction to focus on which rekindled a sense of hope in my parents.

My journey with literacy:

when I was about 4.5, on one magical day, one of my neighbors saw a vehicle which had "Assisi convent for the disabled" written on it. It immediately struck a chord with him and he decided to follow the vehicle. This adventure lead him to a residential center for females with and without disabilities who were provided work, food and accommodation. He then convinced my parents to take me there as it was just 10 KM away from home. Thus, began my literary journey!

When my family decided to take me to Assisi convent to see what they do, I was extremely happy as I loved travelling to new places and have varied experiences since childhood. On the first day, my parents saw people with intellectual, hearing, and visual disabilities and got a peak into their world. My Parents were told that people with visual impairments do read and write. their curiosity knew no bounds to see the tools used to read and write. My mother now recalls that she had ample questions such as How can they see what is written, how do they write in a straight line and so on because the thought of an alternative script never occurred to her. There was only one girl who knew braille. when she brought her braille slate and stylus and started demonstrating, the curiosity of my parents turned into disappointment. As braille involved reading by touch and was nothing like print, accepting this system was overwhelming for my parents. however, when sisters at the convent assured my parents that my literacy in braille would lead to good prospects, they decided that I should give it a try. This convent was a workplace for everyone else, but became my informal school for the next 2.5 years! initially, for a couple of months, my mother accompanied me every day and stayed with me the whole day. after I could manage by myself, my father would drop me to the convent, and my mother or aunt would pick me up every day. During the first month, I was trained on holding my stylus, inserting the paper into the slate, and writing 6 dots. I was also taught to read them by turning the page over. My mother learnt braille in the convent and would teach me at home.

Role of technology:

I was introduced to computers in grade 5 and was taught the basics such as keyboard orientation The screen reader was a blessing for persons with visual impairment, i.e. for those who were fortunate to have access and be aware of it. My knowledge of computers was limited to typing in through the editor with the help of the screen reader software. Between 8th and 10th grade however, I did not use technology to help me study, other than the voice recorder which I needed help to use, as it was in itself was not enabled for visually impaired users.

From 11th grade onwards, the internet became my best friend. I spent hours browsing the web downloading various tutorials to master the usage of various applications through the screen reader. I felt a sense of independence. I could read the news, abundant academic material and the topics of my interest online, listen audio books, convert scanned documents into accessible format using OCR software. I could also socialize with people through Facebook and other means and keep abreast of the developments in the blind community globally. For the first time in my life, mobility was not a barrier to social interactions. I took chess courses online.

Throughout my graduation and post-graduation, I used Skype and Team Viewer to connect with the volunteer tutors who agreed to tutor me after classes from different parts of the world. In 2015, After some trial and error, I got the hang of using the screen reader on the smart phone. It has reduced my dependence on the computer considerably. Though many apps are inaccessible, certain apps designed for the visually impaired such as Envision AI, come in handy. I use voice type extensively for communication through apps such as WhatsApp.

Anita Ghai[2]
In the rest of the section are some excerpts from the Chapter "An Autobiographical Note: on my own journey."[9]

How come you had polio? Were you not vaccinated? Why were your parents not more careful?" These are some questions that always haunt me. Of course, there are many others, such as 'why me?', that all of us always ask ourselves. But what can one reply to these questions? In an effort to defend my parents, and indeed myself, I respond by reeling out factual information about the polio vaccine coming to India in 1959, one year after my birth. There was little my parents could have done. ... I have no memory of an able body. hence, the world that I registered gave me a message that to be disabled is to be defective. ...

As a disabled person, we are products of an ideology of normality where communications of messages of the able body is a constant in any society. As as a result, a disabled person is constantly in a mental state of deferral, awaiting the day the body will not just be mended but cured.

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'Cure' is therefore, an archetypal reality that the disability theory interrogates to understand the impact of the cultural history of polio on individuals.

[2]https://en.wikipedia.org/wiki/Anita_Ghai

... The cultural and religious rendering of disability leads to an obsessive hope and search for cure. ...

Across the 56 years of my live, I have negotiated with shamans, gurus, ojhas, tantric priests and faith healers as well as miracle cures — all to ensure that i could become able-bodied person finally. My first recollection is when, as a child, I was buried neck-deep in such a 'curative' mud at the tender age of eight during a solar eclipse. ...

My family and I took a long time to accept that my disability was permanent and unchanging and different from ill health, which could be corrected and cured.

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After I started driving the hand-driven car, my mobility pattern got transformed. I was elated! However, the aftermath of the post-polio syndrome mandated the use of a wheelchair. The reality of my driving conversely is contingent on caretakers to assist of independence and personhood, me in getting my wheelchair out of the car. For a stranger, this transgression is very difficult to understand. One moment you are autonomous, able to deal with life, the next you are at the mercy of the caretaker, enhancing the experience of helplessness. Poise or self-respect is, therefore, always at stake. There I am, out in the world driving, competing with the speed and zeal of the non-disabled and immediately, a flat tyre can turn me into a pathetic cripple.

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Just as I was beginning to find peace with the challenges of disability, another shock came along in the form of a rheumatic heart disease, followed over the years by several medical episodes that have not just challenged my own being but also raised many questions about the power and status of the medical profession as well as health care for the disabled.

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However, it was not the end of my 'medical journey'. Having gone to a health conference, I decided to go for a mammogram. I took the rest with the belief that nothing was wrong-all women must get mammograms done. Of course, the test would be benign. As I was in the process, the senior doctor requested me to take another test. By that time I was frightened and vulnerable, a scared child concealed in the tired body of a woman pretending to be self-assured. The test report confirmed the fact that I definitely have second stage breast cancer. Trauma was really an understatement. The report devastated my world. It was as if cancer broke up my fused thread of temporality-past converted into the present, and the future lost all its significance. Disability and cancer changed my relationship with my body. My intermittent fight with polio was not as terrifying, daunting and inexplicable as cancer. Psychologically a taboo word, it took me time to understand that the body needed to move on and work through to overcome the 'reality' of cancer but accepting a new mode of living was not easy, Cancer created questions; some of the hidden realities of my body were to become even more transparent that polio could ever make them, I had to acknowledge that this time my enmity was with a formidable foe.

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Research on disability issues has paid astonishingly little regard to the autobiographical narrative, especially of disabled people. Since disability has been a generic term, it has not included o issues, which in my case was heart-related disease and cancer. The reason for engaging with the memories of self and others is critical to understanding disability as cultural discourses offer few affirmative resources for disabled people to draw upon in constructing their personal and social identities. The story of the self is critical. more so if the narrative is marked by extended movements back and forth through 'health' and fitness' and 'ability' and 'disability'. Often, in literature, disability and cancer serve as a metaphor of social breakdown, but in an autobiography, illness is associated with a unique subjectivity because autobiography serves as a self-reflexive tool that helps to highlight personal experience. As a disability rights scholar, I turn to this methodological tool in the hope to offer a solution that is an alternative to the patronizing and marginalizing caricature by others.

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LUDIC DESIGN FOR ACCESSIBILITY IN THE GLOBAL SOUTH

The third author started working on technologies for people with vision impairments (PVIs) about 4 years ago moving to the area with a background in virtual and augmented reality technologies. And predictably the early projects were focused on the disabled in the global North. For example, [14, 1] were about indoor navigation for PVIs. Another ongoing project is to make mainstream video games accessible to PVIs using immersive spatial audio. Several studies were conducted with PVIs recruited from organization in Bangalore. Proper ethics board approvals were obtained, consent forms signed by the participants and participants well compensated for their time with the study. However, the incongruence of the lived realities of the participants and the subject matter of the study was brought home to the author, especially after the second author joined the research team. Our work started focusing on disability in the global south and over the past year, we have evolved a new methodology that we call Ludic Design for Accessibility [17].

We propose that the design of new technologies for people with disabilities should neither be driven incrementally simply by the incorporation of accessibility features into mainstream technology, nor through a function-driven approach that ignores the experience of technology use. We argue for rethinking both the design process and the usage scenarios of accessibility technology around the notion of playfulness and exploration, rather than the received course of utility alone. We propose the notion of ludic design as a framework to rethink accessibility, specifically building on past work on play and enjoyment in the process of interaction with the world around oneself The key premise is that play and playfulness are central to what makes us human, and that by separating playfulness and exploration from the design experience, we fail the intended end users of our products.

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The notion of ludic design for accessibility is of particular importance, as well as of unique challenge, because of the role of play in the lives of people with disabilities. Growing up, children with disabilities may be left out of both the structured and unstructured play (Bateson 2013) for a complicated mix of reasons related to the ways in which formal learning occurs. This can have significant consequences for cognitive development [Holt 2007], including the long-term dissuasion from the idea of learning through play

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Ludic design has the potential to enable people with disabilities in the global south to indulge in play, and while that in and of itself is valuable, the play may result in the eventual acquisition of important skills. The nature of play, that of inducing formation of social groupings is also appropriate in many parts of the global south that still rely on community-based living experience where the units of support are neighbors or villages, rather than families arranged into nuclear units (Ghai 2017).

Over the past year we have been applying the Ludic Design methodology to efforts to introduce digital skills and computational thinking for children who are BLV. Early results of the work are reported in [8] and in [?]. These projects involve a diverse set of researchers, including two who are blind, working with children and many teachers who are also BLV. One of the early insights from our work is that the play and playfulness appear to gel well and actually thrive when faced with factors which are normally viewed as deficiencies and challenges in the global south (lack of teachers, curricular infrastructure, heterogeneity of the student body, etc.

In summary we would like to invite the HCI and assistive technology community to include the perspective from disability studies in the Global South. We believe that such an approach enhances the solution space as well as potentially result in solutions that can actually be deployed at scale around the world.

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