The Upside-Down Politics of Access in the Digital Age

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What's wrong with this picture? We are looking at the inventive Dimitri Bibkow a Russian wheelchair user who built his own DIY wheel chairlift—he is suspended on the outside of his apartment block. He did this after waiting SIX years for the local authorities to install an elevator in the five story high building where he lives. Of course, Bibkow is showing a degree of inventiveness we find over and over exhibited by disabled people who make their own access in the analog world. With a small crew, Bibkow ended up constructing the wheelchair lift himself.

Now many of us know what the problem is. This man needs an elevator. We ALL understand THIS kind of problem with access in the material world. As we close this conference today, I want to speak about access, but construed somewhat differently than we've been hearing for the last four days. I think Bibkow's obstacles are obvious. While we are all sensitized to this kind of problem with access in the analog world, I want to turn to the digital realm. But, I want to ask:
Why is digital access for disabled people not better known?

To begin to think through this question, I'd like to tell you a fairy tale about access written by Vic Finkelstein, a South African wheelchair user and anti-Apartheid

activist, in 1975. "What," Finkelstein asked, if we designed an "upside-down world created for wheelchair-users?" (Finkelstein, 1975). Now Bibkow's problem we can understand all to well. But Finkelstein imagined a very different world. This was a village shaped entirely around wheelchair-users needs. As opposed to the real world, he proudly announced that all residents here would be chair users. And here, he proclaimed, they could finally "control all aspects of their lives." In this small utopia "they make the goods that they sell in their shops with special aids, they work the machines that clean the street, run their own educational colleges, banks, post offices, and transport system." Of course, in this village a resident like Bibkow—that is someone using a wheelchair--was not just normal, but also just "like everyone else in their world of people that she or he meets in daily life."

Naturally enough, in THIS village the very vocabulary of architectural and design forms might change. For one thing, in a world of wheelchair users, everything could be lowered (and I'm showing you here an early design by the Ron Mace, a proponent of universal access movement, showing how a public telephone could be lowered). In fact, Finkelstein speculated that wheelchair using architects would realize that all ceilings and doors could be dropped in height. Now, Finkelstein posited, "there is no need to have the ceilings 9ft tall. or the doors 7 feet in height. It becomes standard practice in this village for doors to be designed to a height of 5ft. The ceilings of rooms can be 7ft.tall. NOW everyone is happy in this village, all the physical difficulties in the environment have been overcome . . . " But so far, Finkelstein's story was really only a thought experiment. The real provocation came

next. "What, he asked, would happen to able-bodied people who might choose to live in this village too?

For Finkelstein, this story represented a form of upside-down politics. It was, of course, presented as an extended thought experiment. It appeared in a larger article that explored the social nature of disability. But in this situation, he might argue, people like Dimitri Bibkow would become the norm, and buildings would be made with them in mind. And-- to take this thinking one step further, in a world configured THIS way (I'm showing you further drawings by Mace outlining building accommodations for wheelchair users), non-disabled people would themselves become the misfits. When non-wheelchair users initially arrived in this imaginary village, Finkelstein continued, "one of the first things they noticed was the height of the doors and ceilings. They noticed this directly, by constantly knocking their heads on the door lintels." Seeing how the non-disabled members of the village went about with dark bruises on their foreheads, the village doctors, themselves wheelchair users, fretted that non-disabled people could suffer from a "loss or reduction of functional ability." Thus "handicapped," special aids like helmets and braces were developed for non-wheelchair users. But still, Finkelstein added, they stood out and "when they sought jobs no one would employ them." In time, voluntary "societies were created to collect charity and many shops and pubs had an upturned helmet placed on the counters for customers to leave their small change." The situation was strained. Only when the non-disabled residents got together did they realize that their "disability" had a social solution—the wheelchair users needed to change door and ceiling heights. In the end, Finkelstein speculates, "The able-bodied disabled"

began to hope for something better: "perhaps, just perhaps, their disabilities could be overcome (and disappear!) with changes in society" (Finkelstein, To Deny or Not Deny Disability, 1975).

Now when I teach about disability, I often start with this fairy tale because it is so easy to understand. Finkelstein had already been engaged in a long effort to extend civil and human rights –first to Africans when he lived in his home in South Africa, then to disabled people when he moved to the UK. But Finkelstein's stroke of brilliance was in presenting an "upside-down world" –a place in which impaired people suddenly seemed able-bodied. Everyone who was not a wheelchair user can immediately understand the problems we'd face if all ceilings were 5 feet tall. And the idea of always having to wear special braces or helmets so we could fit into t his world seems unconscionable. But—by implication-- it also highlights the ways that people with impairments must adapt themselves to fit into the larger, normative world.

This upside down world, however, doesn't present an answer to my original question-- Why is digital access for disabled people not better known and more often applied?—One could, that is, argue that at least part of the reason is that there have been no Vic Finkelstein's writing -- there is no equivalent of this fairy tale written about disability in the digital realm.

I am not going to do that here today. But I do want to discuss how these ideas have

bearing on our conception of digital access. To do that, I am offering to you a series

of questions:

1. What is access for disabled people in the digital realm?

2. Why is this so little known?

3. can this change?

AND FIRST, LET'S APPROACH THE QUESIOTN OF access: What is access for disabled

people in the digital realm? I ask this not in a rhetorical way, but I find that many

people have many different answers. But most don't associate the term with

disability. And certainly part of the problem lies in our perception of technology

today. Generally speaking we see technology as something that conquers disability.

That is, there are powerful technologies now available that can enable all kinds of

assistance. We hear, for instance, how robotic exoskeletons can help paraplegic

people walk, ipads allows persons on the autistic spectrum to communicate

verbally. And then there are the devices that can convert text to Braille in real time

as well. There is a gee whiz factor about these things and it's hard not to love them.

In fact, we tend to regard the digital AS INHERENTLY accessible. I find

among my students a natural assumption that in all things digital, the Road is open

and paved for everyone. . . From VR to the web to other immersive—and digitized—

environments—I suspect that most people are easily seduced into thinking that

digital spaces are available for everybody. Of course a host of economic and social conditions tells us otherwise. But this is doubly the case with disability… No one – I've been told--needs be a wheelchair user in Minecraft.

In fact, in terms of disability, digital access is a complicated thing. Simply put, digital access means making computer hardware and software accessible. And it tends to lurk behind UX and be seen within the province of coding. Furthermore, the digital realm does not enable everyone equally.   In fact, visually impaired people encounter multiple problems when they approach VR or the web . And people with cognitive impairments suffer from poorly organized sites. In terms of movement or motion impairment, the term "ambulatory" refers to those who cannot operate the finely tuned mouse or keyboards most people take for granted.

At the same time, however, I should point out that making accommodations for digital access is not complicated. IN fact, even just knowing the issues at hand can effect remarkably simple change. And this holds not just for web access, but the creation of eBooks, pdfs, video and a range of formats all-important to us as digital humanists. Frankly, some of these steps seem so obvious that they really are just a function of awareness. We've all, for example, had experiences—often on YouTube—where automatic captioning programs work but provide garbled transcriptions; simply just double checking and editing the closed captioning can, for example, be of enormous help for hearing impaired persons. In other cases, it essentially means making sure assistive technologies like Apple's VoiceOver, which is a desktop screen reader, is working efficiently. Now, my talk today is not meant to

delve deeply into these kinds of prescriptive measures. I know that some of our colleagues (like George Williams) have worked and even consulted on this. Right now, I want instead to think through the implications of these kinds of access for us, as digital humanists. Most people – including designers and developers as well as academic researchers —are scarcely aware of them. To go back to Finkelstein's upside down world, we are very like the wheelchair users in that village—unable to think outside a simple "norm." But we hardly need to be living in Finkelstein's wheelchair village to get it: the environment (analog or digital) can make anyone disabled if it isn't configured with them in mind.

But this brings us back to my second question: why is this so little known? Indeed, what is this thing "access" that we are talking about?? As we have heard through this conference, access means different things to different people. In spite of it all, we still lack a robust theorization of access. In a dictionary, accessible is most often defined as something "capable of being entered or approached" In fact, some of the deepest probes of "access" and its implications have been done in disability studies. Here, the disability studies scholar Tanya Titchkosky relates, the word has bigger implications. It can be linked, she argues, "to a complex form of perception that organizes socio-political relations between people in social space" (Titchkosky, The Question of Access, 2011; 4). IT is, Titchkosky points out, "tied tot he social organization of participation, even to belonging itself. Access not only needs to be sought out and fought for, it must be legally secured, physically measured, and politically protected. Access, from the point of view of Finkelstein's

generation, is absolutely fundamental. It is a Right. For this reason, "access" remains a lynchpin in Civil Rights law.

But, to go back to my question ("why is this so little known?) part of the problem is that digital "access" itself has changed remarkably -- even in our lifetimes. To some it's the a ability to download complex web pages in a matter of seconds while to other people digital access means five bars on a cellphone all the time. For others, it is being able to watch a movie stream without any hiccups. For me, the notion of "Access" in the digital humanities has personal roots. In fact, until about 1976, if you'd asked me what a computer looked like, as child I would have drawn a picture of a window in a wall in a lab somewhere. Ant that, too, was shaped by this notion of access. . . That's because my father—George Guffey—was working in an early version of the digital humanities. Beginning in the late 1960s, my father spearheaded something that was being called "humanities computing" at UCLA, where he taught. There he worked with the school's affiliated Clark Library and it was there that they started a series of projects akin to Roberto Busa's groundbreaking work. I know that our colleague Stephen Brier has written about UCLA's early computing efforts elsewhere. As part of this, my father was compiling these vast concordances of the works of seventeenth-century English poets like Traherne and Marville (I am showing you hare one of those volumes, originally published in 1974). For THEM, access to computing meant access to something akin to a drive through window in a lab that was running at two o'clock in the morning. They would fill out these Fortran Coding Sheets, which a keypunch operator (most

likely female coders were working on the other side of those anonymous windows) and transcribed them onto punch cards. Each line of poetry or prose was recorded on a punch card. Even now, if you open up these books, what you see are the readouts of this computing. In some ways, these look unprepossessing today. But I can tell you that it was a struggle even to produce something like this. The huge IBM mainframe computers on campus were being used for highly specialized mathematics and physics

In fact humanists were often hobbled by computing systems that were not built with them or their work in mind. Furthermore--at this time digital access for researchers in the humanities revolved around getting administrative permission to use these powerful mainframe computers. And this meant gaining security clearances and then negotiating complex fee structures. (they still had to purchase the time they needed on these computers). And even the system was often overloaded with users and suffered near constant mechanical failures and was often undergoing repairs.. If the computer happened to be down at the time you'd booked it, that was that. And of course, you never actually saw the computer itself. You bought your time and filled out stacks of Fortran sheets which you delivered to a window in a lab.

Now, I would argue that Access for my father's generation and those early efforts at UCLA was all about getting to the campus mainframes. But I want to move for a moment away from digital humanities and computer access because, for me, the idea of Access has shifted, AND for me it has taken on a different, deeply personal

meaning. Born with cerebral palsy, my introduction to access is through what is

called a "mobility disorder." But I only first started to seriously consider access itself

when I started to think about this sign. Familiar to all of us, I will point out that it is,

in fact, called The International Symbol of Access. Now, I should tell you that, as a

disabled person, I love this sign. In fact, my attachment to it comes from the fact that

it's been a lifeline for me in all kinds of ways. It has allowed me to live a full life. It

has allowed me to be here today. But I never thought seriously about the

International symbol of Access until it was recently changed in NY and CT. In both

states it has been officially replaced by this: AIP. The newer symbol, of course,

echoes the rise of a disruptive, participatory disability culture. The AIP thrusts its

wheelchair user into a more active and dynamic role. With the grace of a wheelchair

athlete, its figure pushing itself headfirst, leaning dynamically to propel itself

forward. It's a symbol that Finkelstein probably would have loved. Seeing it, I

became interested enough to start probing the symbol's history and its politics.

Indeed, as I started doing more research I discovered the huge disconnect

over this term "access." Of course, to my father, access was all about information

processing. To the founders of the nascent digital humanities it meant getting to use

powerful computers to process information. But, at the same time, activists like

Finkelstein were reconsidering what access meant in the material world. —That is,

disabled activists were beginning to lobby for access to education, to public spaces,

and a variety of other functions of Civil Rights.

With all of this in mind, let's return to the problem of digital access and why

it is so little known today. I believe that part o the problem with digital access is that

it's hard for non-disabled people to understand or even see it. And the genius

behind Dimitri Bibkow's wheelchair lift is that he built it outside his building: rather

than have friends carry him up and down the staircase, inside, this DIY elevator is in

plain site. And see it we can immediately understand the difficulty of living on the

5th floor of an elevator less building if you are using a wheelchair. So too when we

read Vic Finkelstein's wheelchair village fairy tale, we immediately grasp the

problem—the environments we ourselves Make can empower or disempower

people.

In fact, in my experience, many of the problems I encounter with lack of access in

the material world—especially mobility access—are quite visible. There, for

example, is a whole twitter feed on ramp fail, with dramatic and self evident photos

of wheelchair ramps that end in stairs, are steep grades impossible for a wheelchair

to navigate, or are obstructed by walls, or posts and other ill-considered barriers.

We are sensitized to the problem of wheelchair access today. We all know what it

should be, and we all can recognize it when it's not there. But digital access for

disabled people is different. I think we all think eBooks, digital archives, and the

Internet as compelling for their power, reach, and ease of use. But again, the digital

realm has no real equivalent to wheelchair ramps. In fact, I suspect that most

people don't even think about it at all. ….We know a ramp failure when we see it.

But Digital ramp fails also exist. . . , but what they are is less well known. . .

With this in mind—and going back to my original point--I should add that Digital

Access is not a complex thing nor is it expensive. It's really more a mindset than a

skill set. It really could—and should—change. We as humanists often work with people who do the back end in helping launch our digital projects. But the truth is that most designers and developers don't even know of this issue. And frankly, when the problems and solutions are discussed, most people are stunned by how simple these protocols are.

To begin, you can actually do simple audits to assess if we are actually creating access or impeding it. It used to be that the process of testing for accessibility was tedious and confusing—the province of developers who had prior accessibility knowledge. But in the last few years there's been a move to change this and there have developed a couple of online sites that are simple to use. This is one, and it helps point out simple issues like text shading, tags for images that enable screen readers, etc. This one was recently created by The Khan Academy. It is "tota11y" which they call "an accessibility visualization toolkit" and it's got a user-friendly VISUAL interface. It's also licensed through MIT. In terms of people aiming to reach out specifically to us academics, I've been in conversation with TeachAccess, which is a consortium of tech companies looking to academe to train students and professors in these measures. They too offer us a whole page of links to audits like WAVE.

But I'd also suggest that we need better models of best practices, I'd turn to something like Sara Hendren and Caitrin Lynch's Engineering at Home, which is a digital archive of a series of adaptations made by a disabled persons in her own

home. It is meant to demonstrate the agency of disabled people in adapting and modifying their own environments. It is not only a digital archive, but also serves then as a platform for making an argument for a robust reconsideration of assistive technology. It also introduces us to Cindy, a woman who had a massive heart attack while on vacation and went into a comma. She had several amputations during this time, and--when she awoke--she found she had a drastically different body. Cindy entered into a lengthy discussion with her insurance company and eventually was given a myoelectric arm. Here she is with it. But, as the site's researchers discovered, she was dissatisfied with it. Instead, she found she could manage better with simple adaptations of household wares she already owned. The site archives those adaptations. Bu it is also s a well conceived example of digital access. And, of course, if we were to do a digital audit, we can see that it passes through the Wave access check fine.

So far, by the way, I've only been talking about digital success stories. But much of the Internet in particular is filled with digital failures. Instead, I just applied this toolkit to a typical webpage for the news. Now here's a site from a news source that I'm sure you are familiar with. . . But let's take this as a typical webpage. This is a complicated thing. Multiple navigation, headlines, subheads, links to rich media, inserted ads, livefeed for local weather (stuff we take for granted). page is huge (long)=achievement and speed is notable. . . but, judging by the WAVE audit, it doesn't' look like its designers have in mind digital access as a top priority.

To return to my own research, in which I've tracked a history of the Access symbol, perhaps my biggest surprise was to discover that we have no formal language to even talk about this these things. The thrust of my book is about symbols BUT One of the main things I found is that the ISA actually serves two functions. First of all it does label and mark accommodations like automatic doors and special parking places. But it was created to fill a second function as well. It is meant to be educational too. That is, it reminds us of the ways in which the environment has to be adapted for disabled people. It announces accommodations. But it also helps us see and understand ramp fails. And I just want to point out that these issues are so little discussed that we don't even have an agreed upon symbol to denote digital access.

Finally, in closing, I would say that there is little legal oversight in this subject. In the US, we have the very idealistic Americans with Disabilities Act (here being signed into law in 1990). And, like much US law, it aims high but the government and usually enforced fully only when adjudicated through the court systems regulate oversight. Enforcement-- even in the built environment --is hit or miss and the guidelines here are loosely written. Even more troubling, there's now a move to undo parts of it. In fact, just last month the Justice Department under the Trump Administration has signaled a major change of policy and has placed web accessibility on something that the new DOJ is calling its "regulatory inactive list".

This, of course, is part of the Administration's larger effort to reduce a number of regulations in development. But it also signals a larger backing off from oversight of the ADA in multiple areas, but with particular emphasis on the digital realm. The latter, the argument goes, is a source of economic growth. The fear is stifling e-commerce. OF course, the argument there goes, if digital access is important for disabled people, the market will see that as a need and—as their buying power is felt—lack of access will make an impact on companies' sales. That is, if private industry wants disabled buyers, they will meet this need by making ecommerce more accessible on their own.

But practically speaking, in the US it means that there will be no regulations or guidance for accommodations for state and local government websites for at least the future. You could say that just as digital access has begun to break out of neglect, it has been obviated. It's not going to be forced on anyone. I don't know what is going to change this situation. Sometimes I think what we need is the digital version of an outdoor elevator like the one Dimiti Bibkow created. Is this something to take up in the digital humanities? Perhaps. But even here the potential rests in us. If we get the word out.