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ONLINE SHARING OF OFFLINE DO-IT-YOURSELF ACCESSIBILITY HACKING PRACTICES

Jerry Lamont Robinson
Syracuse University

Introduction

Labels and their meanings are socially constructed and reinforced by the shared norms, structures, systems, and discourses of powerful social groups. This is especially true when it comes to hackers, disability, and technology. Although the term *hacker* originally referred to a highly skilled and "quirky" individual driven by a desire to achieve brilliant and innovative technological feats through machine manipulation [1] it has deviated from its original connotation due to the influence of the news media, government agencies, for-profit entities, and cyber crime victims wanting to justify greater spending on security and sanctions for hackers with malicious intentions [2]. In the same way that the voice of hackers with good intentions has been overpowered by discourses that opposed malicious hacking the needs and opinions of persons with disabilities are often ignored when institutions that provide products and services to them operate based on certain disability discourses. This study will add to our understanding of the politics of disability associated with rehabilitation technology, durable medical equipment (DME) assistive technology (AT), and technology funding agencies by exploring the DIY and hactivist-like activities that individuals with disabilities engage in offline and discuss online.

Competing Discourses on the Construct of Disability

The construct of disability is politically contentious for a number of reasons. Medical, corporate, consumer and other common disability discourses are built on certain assumptions about what it means to be disabled and can inform the provision of service to people with disabilities [3]. For instance, medical discourses attribute disability to the individual and associates it with terms like body, patient, cure, rehabilitation, impairment, deficiency, physical incapacity, functional loss, and diminished personal responsibility [3, 4]. Medical model discourses often lead to different forms of disablism, or discriminatory, oppressive, or abusive treatment of persons with disabilities rationalized by the belief that they are inferior to everyone else [5]. Corporate discourses on disability are common among rehabilitation professionals and are most evident when these individuals implement initiatives or introduce products and services that meet the letter of the law with regard to medical discourses but fail to address

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social, economic, and other challenges that disabled individuals actually face in society and everyday life [3, 4]. When entities that are supposed to serve persons with disabilities are guided by medical and/or corporate discourses they run the risk of simultaneously ignoring the actual needs and capabilities of consumers and perpetuating societal and structural disablism. Consumer discourses assert that individuals with disabilities have a right to be heard and included in mainstream society [6]. In these discourses categories of objects and services such as DME and AT are positioned within larger discussions about their meanings, the personal identities and relations they afford, and the contradictions within them [7]. Although it is not possible to assess the actual assumptions that AT, DME, and technology funding professionals hold regarding the construct of disability without speaking to them directly it is possible and advisable to juxtapose consumer discourses with common medical and corporate norms, structures, and systems in order to highlight the frustrations that consumers face related to their acquisition, use, maintenance, and repair of AT and DME [4].

DIY Accessibility

DIY accessibility can be defined as the self-driven efforts of consumers to address everyday accessibility, impairment, and disability related issues using individual, collective, or third-party solutions. Similar to the ways in which the Internet allows hackers to collaborate, communicate, and share resources persons with disabilities use online spaces to gather and share information about their offline DIY accessibility activities, artifacts, and practices. Spaces that afford opinion sharing and/or asynchronous discussion about AT/DME object, stakeholder, and funding agency experiences serve as mediums for consumers to describe and discuss how different disability discourses not only are embodied in AT and DME artifacts and related services but also influence the use and DIY behaviors of consumers with disabilities. The proposed study will rely on existing data from three different online spaces with different levels of user engagement to answer the following research questions: 1. What DIY-, hacker- and hacktivist-like activities, artifacts, and practices do persons with disabilities describe online?; 2. How are conventional notions of hacking reflected in the online DIY accessibility content?; 3. What disability discourses and ableist norms are codified the DME and AT artifacts designed for use by persons with disabilities?

Methodology and Data Sources

Data will be collected from the Hackability Blog (http://www.hackabilityblog.com/), Spinalistips forum (http://www.spinalistips.se/tipcategories.html), and Wheelchairjunkie forum (http://www.wheelchairjunkie.com/forums). The Hackability blog is managed by a woman who shares her own DIY hacks and opinions as well as the hacks of others. The spinalistips forum has a collection of DIY accessibility "tips" with detailed descriptions and pictures. The WCJ forum affords asynchronous communication among users. The data corpus will include all hackability blog posts, 10% of the tips in each spnalistips content category, and all relevant Wheelchairjunkie forum threads over a two-year time period. Data from each site will be analyzed and coded for evidence of DIY, hacker, and hacktivist-like activities, artifacts, and practices using a modified and integrated version of Haddon's Types of Innovation and Vincent & Haddon’s Innovative ICT Use frameworks [8]. Wheelchairjunkie threads and Hackability blog posts will be

content analyzed and coded based on general themes found in the hacker literature and definitions of common disability discourses.

Expected Findings

Preliminary findings suggest nine distinct categories of DIY accessibility activities, practices, and artifacts across all data sources (see table 1 below) as well as several traces of common hacker culture themes such as adherence to the tenets of the Hacker Code, demonstrations and exchanges of creative ideas and feats [1] and exploration and experimentation fueled by intellectual curiosity [9]. Somewhat similar to the ways in which hactivists use the Internet to fight against political oppression and "defy the tendencies of established powers to overreach and exploit without accountability" [1] results should elucidate how the Internet aids individuals with disabilities in their individual and collective battles against disability discourses that undergird DME, AT, and funding agency products, policies, and practices.

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DIY Accessibility Practices	
Practice/ Hack	Definition
Artifact Hack	*Artifact Hack* : Specific activities associated with redesigning, reconfiguring, or improving existing object accessibility, usability, and/or general usefulness for anyone who has a functional impairment.
Artifact Innovation	*Artifact Innovation:* Designing accessible new objects. Creating innovative accessible objects that did not exist previously or did not exist as described
Bricolage Hack	*Bricolage Hack:* To cull together two or more different objects and assemble them in a way that addresses a need/want of an individual who has a functional impairment or any object accessibility, usability, or general usefulness issue
Creativity/ Expressiveness Hack	*Creativity/ Expressiveness Hack:* Practices or products that enable or embody artistic, creative, or general self-expression by an individual with a functional impairment
Practice Hack	*Practice Hack:* Any object- or goal-oriented non-commercially conceptualized, developed, perfected, or performed practice or interaction technique that enables someone to engage in an activity that was previously unfamiliar, difficult, or impossible or to engage in or to engage in familiar activities in adapted ways
Maintenance Hack	*Maintenance Hack:* General advice, suggestions, activities, or products that enable someone to repair, replace, adjust, monitor, maintain, clean, protect, modify, re/program, transport, overhaul, or assess the condition and performance of durable medical equipment, assistive technology, vehicles, or various DME/AT parts and accessories. Includes specific activities, expert advice, technical information, suggestions, and product/service referrals
Pattern of Use Hack	*Pattern of Use Hack:* Development or implementation of human-to-human, human-to-computer, or human-to-object interaction practices and patterns that address functional impairment or other related issues
Non-disability related hack	*Non-disability related hack:* A modification, practice, service, or general product that can be used as-is (or close to as-is) by someone with a functional impairment. Hacks in this category may not have been explicitly and exclusively designed to address accessibility or functional-impairment related issues but are none-the-less useful to someone with a disability.
Novel Use Hack	*Novel Use Hack:* The adoption and/or adaptation of a general consumer product or service, assistive technology device, durable medical equipment device, or any combination of the four to address either functional impairment related challenges or general issues that are complicated by the specific functional limitations and environmental context of someone with a disability

Table 1