Cyborg Perspectives on Computing Research Reform*

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ABSTRACT

Recent exposures of extant and potentially discriminatory impacts of technological advancement have prompted members of the computing research field to reflect on their duty to actively predict and mitigate negative consequences of their work. In 2018, Hecht et al. proposed changes to the peer-review process attending to the computing research community's responsibility for impacts on society. In requiring researchers and reviewers to expressly consider the positive and negative consequences of each study, the hope is that our community can earnestly shape more ethical innovation and inquiry. We question whether most researchers have sufficient historical context and awareness of activist movements to recognize crucial impacts to marginalized populations. Drawing from the work of feminist theorists and critical disability scholars, we present case studies in leveraging "situated knowledges" in the analysis of research ethics.

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Sidebar 1: Excerpt from Hecht et al. 2018

"Consider a researcher who develops a new access technology that supports people with disabilities in independently doing something that used to require human help. This technology may dramatically decrease the cost of providing this support and make the service more easily available to people who need it. However, if the services were previously provided by an employee, the new technology may lead to fewer jobs. Also, this technology likely does not have a social component, which users of the service may have highly valued, but which is now unavailable to them. The researcher who develops this technology would be required under our recommendations to enumerate not only the benefits to accessibility, but also the negative impacts on employment and social interaction. The researcher would also likely choose to highlight policies or new technologies that could mitigate these negative impacts (e.g. the integration of remote social support technologies)." [13]

> "Can you make anything in the absence of who you are?"
> – Juan E. Gilbert

INTRODUCTION: WHAT CAN CYBORGS TEACH COMPUTER SCIENTISTS?

In March of 2018, Hecht et al. released a controversial proposal calling for changes to the computing research community's peer review process [14]. Hecht et al. sought to foster community-wide accountability to the global social good by dedicating attention to earnest evaluations of our research's negative potential impacts. Intentional, rigorous analysis of the ethical dialectic of our work, they argue, is essential to "make meaningful progress towards a style of computing innovation that is a more unambiguously positive force in the world" [14].

Hecht et al. provide examples of how this proposed change to author and peer-reviewer responsibility may apply to various computing research fields. Shown in **Sidebar 1**, the authors' example for the accessible technology (AT) field inadvertently illustrates a deeper problem in the computing research community's approach to technologies for disabled people.

This example objectifies the disabled person as a site of employment for an able-bodied carer rather than as an autonomous user of technology. The negative impacts to society are framed as economic impacts to an exclusively able society and social connection as charity. Though such a technology may allow the disabled user to pursue their own employment or mutual social engagements, this impact is somehow inconceivable to the authors. The authors have all consented to speak from an able-normative positionality.

Hecht et al.'s desired transformation of review protocol is not possible without addressing our field's diversity problem and the essential nature of "situated knowledges" in analysis (defined in detail below). How can one adequately reflect on the possible consequences of prediction algorithms in criminal justice [26] without being skeptical of prisons themselves (if not radically abolitionist)? How can one understand the problem beneath 'making algorithms fair' to racialized, gendered, and classed data (living people) without also understanding that predicating an individual's future on the statistical aggregate of strangers is never ever going to be fair?

The term "situated knowledges" was described by Feminist philosopher Donna Haraway in the late '80s as a means of understanding that all knowledge comes from positional perspectives. Our positionality inherently determines what it is possible to know about the object of interest. Situated knowledges recognize that modern fantasies of objectivity have historically rendered the white male as the invisible default witness to scientific fact. Comprehending situated knowledge "allows us to become answerable for what we learn how to see" [12:583]. Without this accountability, the implicit biases and societal stigmas of the researcher's community are twisted into ground truth from which to build assumptions and hypothesis. "[C]oming to terms with the agency of the 'objects' studied is the only way to avoid gross error and false knowledge of many kinds." [12:592–593]. Objectivity is a myth.

Presuming our subjectivity can be erased or elided for the benefit of our research leads us to erase and elide how our implicit attitudes and biases impact our obsservations and interpretations. To break through the tyranny of false objectivity, we must recognize that none of us are capable of the self-invisibility required to occupy the position of "Modest Witness" (see **Sidebar 2**). We must embrace immodesty, claim our positions, and approach inquiry with humility and grace.

Sidebar 2: Myth of Modern Objectivity

"This self-invisibility is the specifically modern, European, masculine, scientific form of the virtue of modesty. This is the form of modesty that pays off its practitioners in the coin of epistemological and social power. This kind of modesty is one of the founding virtues of what we call modernity. This is the virtue that guarantees that the modest witness is the legitimate and authorized ventriloquist for the object world, adding nothing from his mere opinions, from his biasing embodiment. And so he is endowed with the remarkable power to establish the facts. He bears witness: he is objective; he guarantees the clarity and purity of objects. His subjectivity is his objectivity. His narratives have a magical power-they lose all trace of their history as stories, as products of partisan projects, as contestable representations, or as constructed documents in their potent capacity to define the facts." [13:224]

Cyborgs are consequences

Cyborg: Positionality, not Metaphor

The Cyborg referenced here was birthed as figure for feminist analysis of social, cultural, and natural collective phenomena. The Cyborg's theoretical mother, Donna Haraway, describes cyborgs as "maps of power and identity" [13:38]. That is to say that they are graphs, linked lists, meshes, assemblages, agencement— "relations of patterns" [24:57]. The Cyborg figure encapsulates a consciousness dependent upon the disruption of boundaries between organic matter and technology for the constitution of their ontology.

To feminist scholar Jasbir Puar, the Cyborg is at once a manifestation of intersectional subjectivity and a schema which can be traversed omnidirectionally to the concepts and constructs that have formed them. "[A]ssemblages ... ask what is prior to and beyond what gets established" [24:63]. Like 3D meshes in computer graphics, the Cyborg is a model whose rendered product is dependent upon not only the vertices or nodes, but also on the connections between those nodes, the viewer's perspective, and the multi-layered coordinates associated with each node which allows the system to process the color, shading, reflection, and positioning of each node as well as the infinite interstitial space between them.

Jillian Weise provides crucial critique of the Cyborg as metaphoric figuration. Disabled people have long been cyborgs— "those of us with pacemakers or on dialysis, those of us kept alive by machines or made ambulatory by wheelchairs, those of us on biologics or anti-depressants" [37]. Cyborgs are those of us whose life and cognition are reliant and co-constituted by the existence of an interface between flesh and technology. Weise reminds us that the Manifest Cyborg already exist, and we matter. The consequences of technology to our material and existential realities are not abstract, metaphorical, or intellectual— they are necropolitical [21]. Technology and its deployment determine who lives and who dies, and it does so along vectors of societal bias, stigma, oppression, and fantasy.

Critical Disability Studies scholar Alison Kafer seeks to reconcile the cyborg figure with the reality of disabled cyborg life. Medicine and Technology research "are imbued with ideological biases about what constitutes normalcy and deviance" [16:6]. Thus, scientific pursuits of 'intervention' presume the optimality and necessity of a normative end point for the cyborg body— one 'saved' by the approximation of the 'whole' and 'perfect' human, one which is only considered successful if its deviance from the 'natural' presents a superhuman futurity. Living, breathing, critical cyborgs do not ask universally to be indistinguishable from our peers, we seek self-determined and autonomous construction of our interfaced embodiment.

If we are to reconcile Cyborg Metonymy with Cyborgian Identity, we must be responsible for the impacts of both our technologies and our analysis. We must be accountable to the material and existential safety of actual cyborgs. The Cyborg can no longer represent the terminus of computer scientists' aspirations. Cyborgs are consequences, both positive and negative, of research made manifest. To respect Cyborgian ontology we must comprehend the impacts of research past, present, and future.

Sidebar 3: Rewrite of Hecht et al.'s impact review

Consider a researcher who develops a new access technology that supports people with disabilities in independently doing something that used to require human help. This technology may support the disabled person in pursuing their career or becoming more active in their community. However, the technology may also require the disabled user to sacrifice aspects of their privacy and could subject them to heightened state surveillance. As this technology may disrupt the availability and affordability of human care, disparities in access to technology via economic barriers or inadequate insurance policies may widen the resource gap that disproportionately impacts disabled people of color. The researcher who develops this technology would be required under our recommendations to enumerate not only the benefits to accessibility, but also the negative impacts to user privacy and matters of social justice. The researcher could highlight policies or new technologies that mitigate these negative impacts (e.g. new technologies for data anonymization and privacy; reforming insurance definitions of "durable medical equipment" which is often a barrier to accessing AT for disabled people in poverty).

Sidebar 4: Social Prosthesis & Normative Violence

In preschool, [he] struggled socially with other kids. One hit him in the face with a rubber mallet and another in the shoulder with a metal shovel.

"He didn't see it coming," [she] told NBC News. "When you don't look kids in the face, you can't see their reactions or know what to expect."

When he was 5, he was diagnosed with autism.

[N]ow 9, [he] started working one on one with a therapist using applied behavioral analysis, a technique to improve social behavior, but [his mother] saw little progress.

"Nothing really changed," she said. "Until Google Glass." [28]

The Cyborg Perspective

In order to perceive the true positive and negative impacts of AT, reviewers must understand disabled people as agential users rather than as problems to solve. We rewrite the example in **Sidebar 3** to demonstrate the difference. This is just one potential reframing that is possible when you center the disabled user rather than the people that support them. Though there are many possible alternative examples, we provide one more in **Sidebar 5** which highlights a core problem in AT that has often been unrecognized– the potential for AT to inadvertently intensify the oppression of disabled people by digitizing societal bias. In many projects, technology serves to make institutionalized systems of control, surveillance, and segregation of disabled people more efficient rather than empower increased autonomy for the disabled user.

Grounded by the feminist philosophy and critical disability studies work from Section 1.2, these alternative understandings of how AT can impact the disability community are informed the first author's lived experience as a white disabled autistic person. People with diagnosed neuro-developmental disorders and other disabilities and chronic conditions are subjected to systemic violence in the form of normative interventions which foreclose the possibility of societal acceptance of our diverse embodiments [5,22]. Indeed, the interventionist goal of shaping our behavior to match normative expectations are often presented as access itself— for us, inclusion is conditional upon our capacity to perform non-disabled embodiment in public.

The computing research community's recent interest in wearable technologies for autism present normative prosthesis (eye contact training glasses [32,36,38], conversational proximity guides [3], emotion identification coaching [33,34,36], motor tic and stereotypy inhibition [10,30,39], etc.) as assistive devices that afford users inclusion and access to society. This framing of assisted normalization as access legitimizes historical abuses of institutionalization and reminds us of "The Ugly Laws" which denied disabled citizens access to public space on the basis of their "unsightly" difference [29].

In the next section, we will explore the current wearable technology research landscape and make connections to recent work in autistic emotional wellness to understand the possible negative consequences of this research. Then, we will apply Hecht et al.'s review reform to 3 studies in wearable interventions for autism and demonstrate the transformative potential in this reform when coupled with situated knowledges.

BACKGROUND: ELECTRONIC MARIONETTES

The story in **Sidebar 4** comes from a recent NBC news article titled "Google Glass Offers Hope to Kids with Autism" [28]. The story describes a child being routinely victimized by his peers (assault with blunt objects), locates the cause of this victimization within his disabled embodiment ('insufficient' eye contact), and then outlines prescriptions for alleviating his abuse via changes to his person (behavioral therapy and social prosthesis). As is common for medical pathology narratives of disability, 'the problem' is this child's aberrant embodied experience rather than the societal biases that excuse his attackers. Here, assaulting a disabled child is expected behavior, and the disabled child is the deviant in need of intervention.

Sidebar 5: AT as Oppressive

Consider a researcher who develops a new access technology that allows a disabled user to practice exercises from behavioral therapy outside of the clinical setting. This technology may lead to shortened intervention durations, decreased cost of intervention, and longer lasting effects of intervention. However, the technology may also require the disabled user to sacrifice aspects of their privacy and may subject them to heightened state surveillance. Additionally, the technology may also prolong previously unrecognized negative impacts of the behavioral therapy that it was designed to augment. The researcher who develops this technology would be required under our recommendations to enumerate not only the benefits to intervention, but also the negative impacts to user privacy and self-determination. Our recommendations require researchers to consider the historical context of the interventions they seek to augment and engage with disability culture and community about their experiences of normative intervention as violence. The researcher would also likely choose to highlight policies or new technologies that could mitigate these negative impacts (e.g. policies to support community-based participatory research).

The suicidal thoughts and behavior (STB) rate of autistic children has been found to be 28x higher than in the general child population [20]. Autistic adult STB rates have been estimated at 66-75% compared to the general population's 17% [6,7]. Overall, researchers have identified inordinately higher rates of anxiety, depression, suicidality, and general mental-unwellness in the autistic population [6,7,20]. Prior studies falsely attributed these disparities to an inherent predisposition to these conditions [as in 18]. Emerging research has implicated societal and cultural factors at play. Constant pressure from "camouflaging" [6] and "social stigma" [2] have a causal link to mental-unwellness in the autistic population.

Cassidy et al. reveal the statistical variance in STB between the autistic and non-autistic populations can be explained by "camouflaging", trying to fit in, masking, or otherwise attempting to conform to normative social expectations [6]. These suppressing and masking behaviors are learned, according to Botha and Frost, in attempts to avoid stigma, discrimination, and violence [2]. Given that social stigma and normalization appear to be working in tandem to endanger the lives of autistic people— researchers must ask themselves how this might implicate interventions that target "social skills", "behavior shaping", and becoming "indistinguishable from their normal friends" [19:8].

In prior work, we surveyed the ACM and IEEE databases for studies on wearable technologies for autism intervention. 90% of studies we reviewed constituted 'normalizing technologies'— or technologies that attempt to shape autistic behavior toward more neurotypical presentation. Approximately 30% of the technologies were applied to augmenting behavioral interventions, 50% of the technologies were applied to emotional intelligence or social skills drilling, and 10% were for Vocational (Re)Habilitation. The remaining 10% of technologies were applied to domains of emotional and/or sensory regulation, motor coordination, communication, or executive function.

Only 10% of studies reported the use of participatory design (PD) strategies. Three studies included autistic participants in PD sessions. Of those, only 1 [9] contained a detailed description of the participatory process. Other research teams used therapists, parents, or neurotypical children acting as proxies for determining design specifications. Our findings are consistent with Jivraj et al.'s survey of PD in the general body of autism literature [15], which found that out of 636 studies, only 7 included autistic adults and contained clear descriptions of their research roles. Benton et al. [1] explicitly caution against "using proxies, such as parents, carers or teachers, to make design decisions on [subjects'] behalf" [1:3748], noting "if design methods are informed by incorrect assumptions and preconceptions of the neurodiverse community, resulting technologies may serve to further marginalize these groups" [1:3747].

When technologies are designed to regulate affect [11,17,33,35,36], interpersonal space [3], prosody [4], and even inhibit a person's intuitive body movement [23,25,39], the wearer's autonomy and very personhood is undermined. Such interventions preclude an agential cyborgian identity and constrains the wearer as an electronic marionette. The technology serves as a delegate for oppressive social conventions. Even if an autistic person willingly places Google glass on their head, where does that willingness come from? Does it come from an autonomous sense that they need to change their inherent way of being in order to access the world? Or does it come from an introjected sense of deficit? That they do not deserve access unless they can conform?

The following case studies will review 3 research examples featuring wearable technologies for autism intervention. The positive and negative impacts of each technology will be evaluated by centering the autistic wearer as an agential technology user, an intentional cyborg. Positive impacts provide opportunities to the cyborgian user to pursue self-determined interests. Negative impacts endanger the user's autonomy, violate their privacy, and subject them to surveillance and control. Cyborg technologies locate 'the problem' of disability in a callous and often hostile society. They challenge social convention as they constitute new capacities for their cyborg hosts.

CASE STUDIES IN REVIEW REFORM

These studies were chosen from the pool of papers collected for our prior survey discussed in Section 2. These three were chosen not to single them out as uniquely troublesome, problematic, or unethical; but because they exemplify the risk to autonomy inherent in the problematization of disabled subjectivity and because they contain clear voices of disabled resistance from the participants themselves. Below, we will describe each technology, identify resistance in participant voice, and discuss positive and negative impacts to society.

Case Study 1: Wearables as Pervasive Admonishment

Description of Technology. Zakaria et al. [39] provide a "proof-of-concept that uses smartwatch notifications to help children control their behavior without intervention from caregivers" [39:196]. This is achieved via a wizard-of-oz system in which haptic and visual prompts are delivered by the teacher to a smartwatch worn by the autistic student. In a fully realized system, the teacher would no longer need to intervene on self-stimulatory or repetitive behaviors as the watch would prompt the student to self-suppress.

Participant Resistance. "Upon hearing the notifications, he paused briefly to look for his teacher. When he realized the distance, he ignored the command and continued flapping his hands. He did not stop flapping his hands until the teacher personally intervened" [39:203]. Potentially unintended by the study authors, this excerpt illustrates a moment of resistant autistic voice. Participant C5 rejects the authority of the technology to control and constrain his bodily autonomy. Researchers and reviewers alike will benefit from attending to narratives of participant resistance.

Negative Impacts. This technology is designed to persistently reinforce normative bodily movement as well as verbal and gesticular expression. In effect, the technology prioritizes normativity of children with limited oral speech over established non-speech modes of communication. Zakaria et al. themselves report that "these behaviors can be benign and even comforting" and that they may "manifest due to stress, anxiety, or attention seeking" [39:196]. These behaviors are inherently communicative. They express delight as well as distress. To suppress them and neglect attending to their antecedent is cruel at best, and dangerous at worst.

Positive Impacts. If the autistic user had personal choice over which behaviors to monitor, such technology could support self-determined behavior changes via facilitated bodily awareness. Emotional awareness, interoception, and proprioception are all acknowledged difficulties for autistic people [27] . Technology that supports independent awareness of internal affective and physiological states could be invaluable to autistic people.

Case Study 2: Wearables as 5-Point Restraints

Description of Technology. Singleton et al. propose a system of wearable networked devices to assist clinicians in tracking and monitoring the behavior and location of residents [30]. Each resident may be fitted with 5 wearable devices, one for each ankle and wrist, as well as once central node. This constellation of devices is meant to identify the patient's location, physiological state, and classify and catalog a repertoire of physical behaviors.

Participant Resistance. In table 1 of Singleton et al. 2015, there is a list of commonly tracked behaviors at the Heartspring institution [30:790]. Notable entries from this list include resistant behaviors such as "non-cooperation/non-compliance", "inappropriate talk", "stalling", "dropping", and "crying". A reviewer might be curious as to why so many residents are crying so often, among other things.

Negative Impacts. A diagram of the proposed system inadvertently illustrates the similarities between the proposed system and 5-point restraints [30:790 Fig. 2]. Though they are not physical restraints, wearable automation of behavioral tracking and surveillance may have complex impacts on the amount and nature of human contact residents receive. To fully understand the unease this study produces in disability activists, reviewers may require historical knowledge of the Judge Rottenberg Center and the GED (Graduated Electronic Decelerator). The GED is a backpack which delivers electric shock to the wearer that can be deployed by staff at any time for any offense [8]. It has taken decades of activism to get Federal support for banning the use of the GED. Wearable devices in institutional settings have a dark history, a dark present, and a murky future.

Positive Impacts. Such technology might be better suited to counter-surveillance of the institution and may assist in identifying and reporting abuse of institutional residents. Disabled people in institutional settings are at heightened risk for psychological, physical, and sexual abuse. Technologies to hold institution staff and administration accountable for these abuses may save lives and support the abolition of disability segregation via institutional placements.

Case Study 3: Wearables as Emotional Assistant

Description of Technology. Torrado et al. developed a smartwatch application to identify heightened distress in the autistic user and present them with emotion regulation strategies to return them to a calm state [31]. The watch detected spikes in heart rate and sent a notification to the user to alert them to their heightened emotional state. The watch then presented a familiar calming strategy authored by caregivers via a companion smartphone app. During a small pilot study, the research team found that when the user was able to engage with the app, heart rate spikes were fewer, and returned to baseline more quickly.

Participant Resistance. Participants did not always attend to the watch's presented regulation strategy. This apparent resistance can be reframed as the allowance of autonomy. Participants were not forced or coerced into attending to the wearable device. In affording freedom of choice, the technology represents potentials for respectful assistive design.

Negative Impacts. In this study, the regulation strategies are designed by caregivers rather than by the wearer. Though some users may require more assistance than others, all users benefit when they are understood to be the primary creator of their own content. Because the companion app was designed with the assumption that the caregivers would be creating content, the app is likely to be inaccessible to many of the intended wearers of the device. If the wearer has no control over their self-regulation content, they may be less likely to engage with it or may even feel controlled and coerced by it.

Positive Impacts. This technology facilitates emotional awareness as well as delivers an actionable and practical strategy for regulating one's own affective state. Such an assistive device could afford greater privacy and autonomy for autistic and other neurodivergent users and allow them to more confidently approach new settings and social situations.

These three studies each take very different approaches to similar scenarios. By evaluating their positive and negative impacts from a critical disability studies perspective, rather than simply their design limitations, we are more accurately able to address the implications of these technologies for the populations for which they are designed.

CONCLUSIONS

In summary, we have applied Hecht et al.'s recommended review reforms [14] to 3 research designs for wearable technologies for autism intervention [30,31,39]. We highlight how the proposed reforms to the reviewing process may fail to generate the expected results when reviewers do not have adequate historical knowledge or awareness of activist movements from within the participant population. We illustrated how an understanding of Cyborg theory [13,24], and especially critiques of Cyborg theory and technology studies from critical disability scholars [16,37] can assist the computing research community in developing the critical analytic filter necessary to competently evaluate research impacts for the disability community.

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Commentary

For alt.chi paper
Cyborg Perspectives on Computing Research Reform

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I absolutely love this paper personally and professionally (also as a neurodivergent scholar myself). It is not only a precise critique of the many systemic issues with the design of assistive technologies for autistic people, but also an empowering piece written from a place of strength within a community that is often marginalised, even ostracised and definitely othered in HCI research.

The structure of the paper provides a stark contrast to what we are used from CHI papers, but it makes sense to someone with a humanities background and resonates well with my own thought patterns (so maybe, not everything has to be catered to neurotypically presenting readers all the time?).
The author also takes us on a wild ride through their epistemological basis leading into the analysis of Hecht et. al's proposal. Particularly the suggestion and example the author draws on are incredibly telling regarding constructing an ableist 'we' towards a disabled 'other' in the design of assistive technologies, which I had also noticed when first reading it and tried to discuss with the authors. The only point I contest is calling all of these authors non-disabled, as many disabilities can be invisible or masked and, in these cases, not necessarily disclosed. However, the perspective of the example Hecht et al. provide certainly reeks of ableism.

The author also offers alternative options in this space that are oriented towards the needs, desires and rights of disabled people. The analysis of the case studies provides illustrative examples of how positive and negative impact can be assessed from a perspective of critical disability studies, essentially showing how this assessment is tied to an expertise that can currently not be expected from HCI researchers and requires deep engagement and willingness to overcome structural ableism within one's own research.