Reasoning Outside Normative Requirements: Disability and Technology Design

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INTRODUCTION

A central challenge to designing assistive technology is the population problem: often times the user group for any particular design is rather small and the nuances of a good fit can be rather personal. This often means that there is a small market for created technology, and often times, individual differences make it extremely difficult to create a single device design which accommodates a subpopulation's varied needs. Emerging wearable devices and rapid prototyping tools offer promise for adapting and customizing technology to make it more accessible to these diverse subpopulations (*e.g.*, see [12, 13]). These approaches empower users to tailor assistive devices to their own needs as they, themselves see appropriate by selectively installing software or augmenting the form factor of opensource hardware. To support customization, online communities have arisen around these technologies [4]—critiquing accessibility failures where they arise [1]—to exchange best practices and techniques for do-it-yourself (DIY) solutions as well as sharing expertise. The emergence of these tools and the intimate data collection they require raise questions about ethical demands in the technology design research and creation process.

END-USER AGENCY IN TECHNOLOGY DESIGN

Off-the-shelf wearable technologies and DIY methods offer individuals a greater range of resources to draw from to customize technology to their individual needs. For example, the networked connectivity of devices such as a DIY insulin regulator [13] or home activity monitor [11] facilitate data sharing between healthcare providers or care givers and patients when they are not co-located. Yet, these online communities and data sharing increase a person's exposure online. This exposure in-and-of-itself may not be problematic insofar as it is voluntary and reflects social affinities. However, seeding these communities and creating sharing-platforms and the data sharing that is constitutive of these services challenges longstanding practices of treating individuals with impairments with special consideration during the research process. Special precautions include ensuring participants are empowered to fully consent and participate in research or employing methods to protect related health information.

The technology design and adoption processes supported by these communities decentralizes the development process of health technologies traditionally the purview of the medical device industry. Consumer devices are not subject to FDA regulation as they are not medical devices [19]. This process may assist with lowering healthcare costs and provide individuals with exposure to a wider range of opinions and sources of assistive services to better tailor devices to their personal needs. For example, providing an automated screening tool that can be administered without medical expertise can support decision-making about whether additional costs or medical consultation should be pursued [21]. Yet, this approach also operates outside institutional governance of reliable and trustworthy technology design for healthcare applications. For example, the e-NABLE community supports volunteers operating outside of the orthotics industry in sharing and exchanging expertise on 3D-printing low-cost prosthetics to meet the needs of traditionally underserved communities [9]. Convergence of consumer and medical technology design is not problematic per se, and in fact, shows potential for addressing a wide range of important and unmet needs. Rather, these considerations highlight a need for considered design.

REPRESENTATION AND TECHNOLOGICAL MEDIATION

Recent calls for ethical considerations within the HCI community have focused on procedural ethics rather than determining what ethical dimensions should inform technology design that is not subject to federal regulation and how they should be engaged. For example, recent reports highlight questions about whether big data research is human subjects research, and so subject to Institutional Review Board (IRB) guidance [17]; whether offline consent forms should appear in equivalent form online [2]; how researchers interpret and employ the Belmont principles [22]; and what role researcher discretion—especially when working with vulnerable populations—continues to have when all protocols have been rigorously examined and approved by IRBs [18].

However, procedural ethics assumes thick ethical concepts where the scope of ethical questioning has already been determined [23], and so, leaves little room for engaging foundational questions about the role of ethics in

technology design. Violation of IRB procedures is not what is at stake when researchers raise ethical concerns over the design of certain kinds of technology such as whether and how to repurpose data, the formation of online identities through data, and programming social relationships [6]. These questions raise concerns over how to embed ethical considerations in technology rather than the conduct of research itself. For example, it is hard to see how procedural considerations help when determining whether we should automate ethical decision-making through AI assisted ethics [5] or even equip individuals with an ability to surveil to counteract being surveilled [16]. These questions of ethics become acute when it comes to questions of healthcare for individuals whose autonomous decision-making is compromised as is frequently the case for individuals with cognitive disabilities [8].

Employing thin ethical concepts could ground critical reflection on how technology is designed without being overly proscriptive. To illustrate, the creation of assistive technology occurs amidst a long running debate on how disability is conceptualized and how end-users are engaged within the design process. Research on assistive technology can be strongly influenced by conceptions of impairment and what is being targeted for assistance [15]. For example, augmented alternative communication devices might draw "on a theory of the underlying language deficit; and, importantly, the efficacy of [the] device may provide a test of [the] theory" [14]. Theorizing on the role of assistive devices often occurs along a spectrum between conceiving of impairment on a medical model to be addressed by healthcare providers and that of conceiving of impairment on a social model to be addressed by socio-political organizations. HCI research may better support end-users in asserting where along this spectrum they wish technology design to be by affording access to effective participation in the construction and critique of values embedded in technology.

EMERGING TENSIONS AND RISKS
Thin ethical concepts could ground discussion over new concerns and risks emerging around DIY tools and the decentralization of the device design process. By not being proactive in engaging discussions of emerging concerns, researchers risk having their contributions stifled. For example, FDA regulators have voiced concerns over widely disseminating biohackers' DIY methods to others and allowing for opensource techniques to emerge within DIY health device communities [7]. DIY methods serve as paradigm cases in which hackers routinely demonstrate ways in which opensource and networked health technologies introduce new security risks by allowing for malevolent targeting [3]. By fostering critical discussion of these risks, researchers contribute informed rationale and help balance discussion of the trade-offs involved in the technology creation process.

To complicate this picture, the ways in which policies are set may overlook how privacy norms may be unclear and subpopulations of individuals with disabilities may exert influence over debate assumptions. For example, when Google Glass (a popular head-worn display) was released for beta testing, it was heavily criticized for ignoring privacy concerns. Yet, researchers and developers work on wearable technologies amidst variable societal norms with respect to privacy that can be hard to predict and shifting attitudes that adapt quickly with time [10]. This may be even more true in the case of assistive technologies: a recent survey found privacy concerns ameliorated when it was disclosed that the head-worn display was being used as an assistive device [20]. By explaining the thin ethical concepts employed and elaborated in the technology design process, researchers inform public debate about what can reasonably be expected of technology and how technology may be aligned with public goals.

CONCLUSION
In conclusion, wearable devices and rapid prototyping tools offer individuals the ability to customize assistive technology to their own needs. Discussions over the ethical implications of these technologies often do not consider ways in which persons with disabilities may be better empowered to manage their own health and socio-political relations as a result of these emerging methods. Given existing regulatory frameworks and emerging risks that may be at stake in creating assistive devices and fostering DIY methods, it will be increasingly important for researchers to explain and contribute their own research findings to both ethical theorizing and policy making. Before this can occur though, researchers will need to decide what role ethics discussions have in the technology design and creation process.

AUTHOR BIOGRAPHY
Kristin Williams is a PhD student at Carnegie Mellon University. She researches the way language technologies mediate socio-political participation for individuals at the periphery of a language community. Her work frequently focuses on individuals who have language impairments with a neurological basis and the design of technology to facilitate a person's independent contribution to language-dependent exchange. She has an MS in Human-Computer Interaction from the University of Maryland and a BA in Philosophy from Reed College.

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