

Rehabilitation Culture and Its Impact on Technology: Unpacking Practical Conditions for Ultrabilitation

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Abstract

Purpose: It has been proposed that rehabilitation practice should expand its aims beyond recovery to “ultrabilitation”, but only if certain biological, technological, and psychosocial conditions are met. There is thus an opportunity to connect ultrabilitation, as a concept, to adjacent literature on assistive technology and sociotechnical systems.

Method: We draw on insights from sociology of technology and responsible innovation, as well as concrete examples of neural devices and the culture of rehabilitation practice, to further refine our understanding of the conditions of possibility for ultrabilitation.

Results: “Assistive” technologies can indeed be re-imagined as “ultrabilitative”, but this shift is both psychosocial and technological in nature, such that rehabilitation professionals will likely play a key role in this shift. There is not, however, sufficient evidence to suggest whether they will support or hinder ultrabilitative uses of technology.

Conclusion: Advancing the idea and project of ultrabilitation must be grounded in a nuanced understanding of actual rehabilitation practice and the norms of broader society, which can be gained from engaging with adjacent literatures and by conducting further research on technology use in rehabilitation contexts.

Keywords: responsible innovation, assistive technology, sociotechnical systems, disability theory

Introduction

Why aim for “normal”? Buetow et al. [1] draw on personal and professional experiences, academic literature on disability theory, and the concept of flourishing to propose a bold vision for rehabilitation: enabling “human flourishing that moves persons toward, around or beyond recovery of particular functioning.” Scholarship on the ethics of enhancement, post-humanity [2, 3], and a range of social theory on illness and power [4, 5] may be instructive here, but the proposal for ultrabilitation is not primarily intellectual or philosophical. Instead, the authors explore ultrabilitation as a reimagining of *practice*, providing rehabilitation professionals with a set of material, cultural, and institutional reforms to work towards. To this end, they highlight three types of conditions that enable ultrabilitation: biological, referring to bodies and their capacities; psychosocial, referring to entangled mental, cultural, and social states; and technological, referring to new and existing tools and interventions. This multidimensional set of conditions productively directs our attention away from narrowly academic reflection on ethical ideals and towards the concrete realities in which rehabilitation takes place.

In keeping with this practical sensibility, the present paper considers more closely the case of rehabilitative or “assistive” technologies and how they could serve as “technological conditions” for ultrabilitative practice. Drawing on complementary literature in responsible innovation and science and technology studies, we argue that technological and psychosocial conditions of ultrabilitation are substantively linked, affecting one another in practice. Taking the example of a potential ultrabilitative technology, the brain-computer interface (BCI), and its dependence on rehabilitation culture, we suggest that “assistive” technologies *can* serve ultrabilitative goals, but only to the extent that the rehabilitation professionals, among others, embody the openness to ultrabilitation that is prescribed by Buetow et al. [1]. Whether or not they are able to do so is, however, an open question. For this reason, we conclude that moving beyond rehabilitation as currently understood will require a more nuanced understanding of both professional rehabilitation culture and the broader societal context shaping technology use.

Making Ultrabilitative Technology Is Also a Psychosocial Challenge

“Biomedical” and “assistive” technologies, when defined as such, are often associated with the goal of recovery or returning the user to “normal” in some sense. BCIs, for example, are a type of neural technology that is being developed as a response to “personal, social, and economic burdens of [user] disabilities” [6] and have been labeled “restorative” and “assistive” [7]. Taking advantage of the plasticity of the brain, BCI developers devise ways to re-connect damaged motor pathways or provide alternative means of communication. In keeping with the framing in Buetow et al. [1], we could call BCIs and analogous devices “rehabilitative technologies”. But just as the authors imagine rehabilitation expanding to include ultrabilitation, we could imagine the range of applications of rehabilitative devices expanding to include ultrabilitative functions. Accordingly, the label “ultrabilitative technology” will be used to refer to devices that could be applied to reach the realm of ultrabilitation.

In the case of a BCI, it is easy to imagine that the ability to control a computer with one’s thoughts could have benefits beyond or unrelated to a given rehabilitative goal. For example, by controlling a semi-autonomous wheelchair with self-modulated brain activity, a BCI user might be enabled to move throughout the environment; for some devices, the user will select desired direction of movement by visually focusing on a graphical display [8]. This type of BCI may one day be prescribed to a person with motor difficulties, perhaps due to paralysis, with the primary and, as is the concern of Buetow et al., exclusive goal of restoring that person’s previous level of mobility. However, there are other plausible functions and benefits of this technology; the user is enabled to move in ways they could not even before becoming paralyzed (e.g., without physical effort), or their BCI can be connected to other technologies in their environment, such that they can control light switches or home appliances at a distance (perhaps eliminating the need to move at all). These functions are better understood through the lens of ultrabilitation, as even able-bodied users of this BCI would gain new abilities (i.e., mobility without bodily movement) and new ways of accomplishing old tasks (i.e., controlling technologies remotely). This could not be the case if BCIs could only restore the capabilities of those who are disabled to a “normal” level of functioning. It seems, then, straightforward enough to re-conceptualize BCIs as ultrabilitative technologies.

Yet, a simple change in language —“we should make ultrabilitative BCIs” — belies the complex network of values, discourses, and assumptions that make BCIs what they are; as with all

technologies, there is a psychosocial context to consider. Scholarship in the fields of sociology of technology and responsible innovation has suggested that technical systems are deeply shaped by the social context in which they are devised and used. Bijker and Pinch [9] illustrate this dynamic by re-explaining the success of the bicycle. Perhaps contrary to common sense, they argue that the bicycle's effectiveness as a technology was not guaranteed by good technical design alone. To the contrary, 19th century promoters, designers, and users of the bicycle had to negotiate what problem it was meant to solve and whether the bicycle could even do so. The ultimate choice to use the rubber tire, for example, was the outcome of an open-ended conflict between groups that saw the tire as a means to go fast and groups that rejected it due to its requiring too much maintenance and its violation of clean-line aesthetics. Thus, a single successful technology, which we may see as the obvious outcome, hides a range of other possibilities that lose out for primarily social reasons.

Building on this insight, researchers have called for more "responsible innovation" in the present day, prescribing careful consideration of who gets a voice in innovation practices and who is excluded or ignored [10, 11]. Engineers, scientists, and other experts, in particular, are frequently criticized for their narrow framing of societal problems. To return to the case of BCIs, Wolbring and Diep [12] observe that they are primarily developed for "patients". This seemingly discourages their use for ultrabilitative purposes as it gives priority to designs which enable strictly medical usage, to marketing strategies which primarily target the medical community, and to users who are medicalized, or deemed "unhealthy" by the medical community. As a result, those hoping to use BCIs for non-medical purposes may believe that this cannot or should not be done. Worse, framing BCIs in medical terms conflicts with the self-understandings of some disabled persons, who may not see themselves as ill or in need of medical treatment.

What is the solution? Frameworks for responsible innovation prescribe systematic inclusion of stakeholders in the development and use of technology. Just as Buetow et al. [1] recommend partnerships with disabled individuals, the responsible innovation literature dictates that technology should only be created with inclusion of potential beneficiaries and other stakeholders. This procedure is intended to offset problematic assumptions made by experts and to distribute political power more broadly. This leaves open, however, the specific role of rehabilitation professionals. As key stakeholders, how are they likely to shape the development and use of ultrabilitative technologies?

This returns us to a core assertion of Buetow et al [1]: rehabilitation culture does not currently embody the values of ultrabilitation. In keeping with a social understanding of technological development, this psychosocial feature of rehabilitation practice could shape how technology is ultimately used, in several ways. In the case of BCIs, these “assistive” technologies are often developed and tested specifically for clinical use not only by engineers, but also by rehabilitation researchers and practitioners [13, 14]. Such technologies include, but are certainly not limited to, BCI-based prosthetic limbs, which physical and occupational therapists train patients/clients to use [15] and BCIs intended to facilitate communication, to be used by speech-language pathologists [16]. These examples suggest that rehabilitation professionals may be in a position either to advocate for ultrabilitation or perpetuate a recovery-oriented culture, depending on how they understand the problem that is to be solved by technology. We take this to be an unanswered empirical question, but there are a few preliminary observations to note here about the potential entanglements between psychosocial and technological conditions for ultrabilitation.

Rehabilitation Culture Impacts Technology Development and Use

Rehabilitation professionals exhibit many psychosocial characteristics particular to their field, some of which might support ultrabilitation and others, hinder it. Towards the latter, Buetow et al [1] assert that there is “a need for health providers to question and debate the continuing sufficiency of rehabilitation as optimal care”. As an illustration, they highlight the fact that the World Health Organization defines rehabilitation in terms of restoration and seems to rely on a medical model of disability. According to the World Health Organization, rehabilitation is “concerned with restoring and compensating for the loss of functioning, and preventing or slowing deterioration in functioning in every area of a person’s life” [17]. While it is not clear if this definition genuinely represents the attitudes of the rehabilitation community, it may justify a more general worry that rehabilitation professionals understand their work as ending when the client is “species-typical”. There is some evidence in the literature that suggests, for instance, that rehabilitation professionals do (traditionally) adhere to a biomedical definition of rehabilitation, which measures rehabilitative practice by “how closely people who use services can approximate the lives of ‘normal’ people and to what extent they can achieve the skills of able-bodied people” [18]. Despite various movements away from this aim, it appears that historically the rehabilitation community is often willing to link practice to concepts and classifications that are dictated by health science and medical authorities [19]. From our

perspective, this medical framing of practice might run counter not only to ultrabilitative uses of technology, but also to work in (dis)ability studies, responsible innovation, and elsewhere. Worse, it may be oppressive towards the people they are intended to benefit.

On the other hand, many features of rehabilitation practice suggest a rejection of narrow biomedical framings and an openness to ultrabilitation. Patient or client advocacy is an important part of the job for many rehabilitation professionals [20, 21, 22]. They are often aware of, and speak up about, the psychosocial and political barriers that their patients and clients face. They claim to have a responsibility to the well-being of their clients and to society, as indicated on the websites of various regulatory rehabilitation associations and in their ethical codes of practice.¹ More to the point, certain groups of rehabilitation professionals intentionally distance themselves from mainstream medical model-inspired practice [18, 23].

An alternative framework, the International Classification of Functioning, Disability and Health (ICF), is widely used in rehabilitation practice, especially “in the area of medical, social and occupational rehabilitation.” Unlike the medical model of disability, it “conceptualises disability not solely as a problem that resides in the individual but as a health experience that occurs in a context” [24]. This model considers not only physical conditions and limitations, but also environmental and personal factors, such as interpersonal relationships, community life, accomplishments in major life areas, and other things we believe could contribute to human flourishing as defined by Buetow et al [1]: “a process and outcome of persons feeling good (hedonic well-being) in developing and using their human capabilities but also striving to sustain a life of meaning and purpose within their best possible range of functioning.” To the extent the ICF is used, it demonstrates at least a partial shift in rehabilitation attitudes away from the medical model, even if the word flourishing is never explicitly used (as pointed out by Buetow et al [1]) [25].

Finally, and just as significantly, rehabilitation professionals are well-positioned to understand the relationship between a client’s goals and desires and that individual’s quality of life. In some circumstances, this may lead the clinician and the client to set goals that are alternative to, or go beyond, what is usually seen and accepted in medical practice. This unique capacity to set endpoints “beyond fitness” is especially evident in sports physiotherapy and performance

¹ See for example the Canadian Physiotherapy Association website - <https://physiotherapy.ca/cpa-code-ethics>

enhancement [26, 27]. This would seem to indicate that rehabilitation professionals can help clients bypass “normality” and pursue human flourishing. A neural engineer designing a BCI, in contrast, might have limited interactions with potential users of “assistive” technology, never getting to know what is most meaningful to them [28]. Since the aim of ultrabilitation, and in this case, ultrabilitative technology, is flourishing rather than simply ‘getting back to normal’, the close relationship between the rehabilitation professional and the client is compatible with this broader goal. We may still wonder, however, if these features match the reality of rehabilitation practice, which may be negatively impacted by economic constraints and institutional norms.

Questions for Future Research on the Possibility of Ultrabilitation

Overall, an empirical understanding of rehabilitation practice, and more importantly, the culture in which it is situated, could help answer the question we raised above about the role rehabilitation professionals could play when it comes to creating technological conditions for ultrabilitation. In our view, there is not a sufficient body of evidence on this topic; responding to this knowledge gap should be a next step for the ultrabilitative project. Interview or survey studies of rehabilitation practice, among other methods, could provide a better idea of which professionals sympathize with the aim of ultrabilitation, and which would stick to a more restrictive recovery-oriented framework. To this end, there are certain questions for rehabilitation professionals that we deem particularly important for understanding the interaction between the psychosocial and the technological.

Specifically, we suggest that future studies ask practitioners about 1) which model of disability they accept (medical, social, etc); 2) the extent to which their current understanding of rehabilitation involves human flourishing; 3) the necessity of ultrabilitation and specifically, ultrabilitative technology; 4) cultural, economic, and institutional constraints on ultrabilitation; and 5) whether they are aware of any tensions between their views on rehabilitation, technology in rehabilitation, and disability, and those portrayed in the media, or those of potential clients. We believe that the answers pertaining to these questions will help in forming a coherent image of what rehabilitation culture currently consists of and what implications it could have for the future. For example, if the majority of rehabilitation professionals actually report favouring a social model of disability, then we might conclude that ultrabilitative technology would be embraced by the rehabilitation community, who, as a result, might not see a need to *only* return people who are disabled back to “normal”. Or, perhaps more obviously, if rehabilitation

professionals report aversion or inability to use technology to enhance or move beyond recovery, then they are likely to preclude or inhibit technological conditions for ultrabilitation.

To rephrase the above questions in terms of the core proposal of Buetow et al [1], ultrabilitative technology would likely require that rehabilitation professionals 1) adopt a model of disability which does not rely on the view that disability is a deviation from the species norm that must be corrected; 2) have a current understanding of rehabilitation that includes human flourishing, or are willing to incorporate human flourishing in their understanding and practice of rehabilitation; 3) are willing to consider the necessity of ultrabilitation and of ultrabilitative technology; 4) can overcome cultural, economic, or institutional barriers to ultrabilitation; 5) are aware of and amplify voices compatible with ultrabilitation and ultrabilitative technology and/or are aware of and overcome the voices incompatible with ultrabilitation and ultrabilitative technology. To what extent these conditions are realistic is, minimally, an empirical question for future research.

Conclusion

We have argued that, if ultrabilitation is to move from a mere re-imagination to an actual re-configuration of the field, there are concrete conditions that have to be met. Reflecting on some such conditions listed by Buetow et al [1], we observe, on a fundamental level, that the psychosocial and the technological are not fully separable. Rather, the development and use of ultrabilitative devices like BCIs is contingent upon a compatible psychosocial environment that includes rehabilitation professionals themselves. This general phenomenon is well-documented in the responsible innovation and sociology of technology literature, but much less is known about the specific social contexts in which ultrabilitative devices would be designed and used. We highlight this as a possible direction for future empirical studies, which could more fully ground the aim of ultrabilitation in the actual experiences of practitioners.

More importantly, and beyond the question of future research, studying the culture of rehabilitation professionals should cause us to reflect on the broader fit between ultrabilitation, as a prescription for change, and the existing institutions and norms of society. Best practices in responsible innovation of technology would suggest that we should design ultrabilitative technologies in an inclusive way, bringing diverse voices into laboratory and biomedical spaces as early as possible. But, this procedure does not guarantee an ultrabilitative outcome. There are deeply entrenched cultural norms of health and discursive representations of the ideal body [29, 30] that may overpower the values expressed by Buetow et al [1]. Nevertheless, it may also

be the case that many members of the public are open to a re-imagination of rehabilitation and are just waiting for new ideas and possibilities to embrace. In either scenario, the ambitious character of the ultrabilitative project requires engagement with a wide range of scholarship on cultures of health, public attitudes towards technology, and participatory methods of technological innovation.

References

1. Buetow SA, Martínez-Martín P, McCormack B. Ultrabilitation: beyond recovery-oriented rehabilitation. *Dis Rehabil.* 2017 (2):1-6. doi: 10.1080/09638288.2017.1406997.
2. Sandel MJ. *The case against perfection : ethics in the age of genetic engineering.* Cambridge, Mass.: Belknap Press of Harvard University Press; 2007. English.
3. Jasanoff S. Perfecting the human: posthuman imaginaries and technologies of reason. In: Hurlbut JB, Tirosh-Samuelson H, editors. *Perfecting human futures : transhuman visions and technological imaginations.* Wiesbaden: Springer VS; 2016. p. 73-95.
4. Tremain S. On the government of disability. *Soc Theory Pract.* 2001;27(4):617-636.
5. Scheper-Hughes N, Lock MM. The mindful body: A prolegomenon to future work in medical anthropology. *Med Anthr Q.* 1987;1(1):6-41.
6. Wolpaw JR, Birbaumer N, McFarland DJ, et al. Brain-computer interfaces for communication and control. *Clin neurophys.* 2002;113(6):767-791.
7. Soekadar SR, Birbaumer N, Cohen LG. Brain-computer interfaces in the rehabilitation of stroke and neurotrauma. In: Kansaku K and Cohen L, editors. *Systems neuroscience and rehabilitation:* Springer; 2011. p. 3-18.
8. Li, Y., Pan, J., Wang, F., Yu, Z. A hybrid BCI system combining P300 and SSVEP and its application to wheelchair control. *IEEE Trans Biomed Eng.* 2013;60(11), 3156-3166.
9. Bijker WE, Pinch T. The social construction of facts and artifacts: Or how the sociology of science and the sociology of technology might benefit each other. In: Bijker WE, Hughes TP, Pinch T, editors. *The Social construction of technological systems : new directions in the sociology and history of technology.* Cambridge, Mass.: MIT Press; 1987. p. 11-45.

10. Stilgoe J, Owen R, Macnaghten P. Developing a framework for responsible innovation. *Res Policy*. 2013;42(9):1568-1580. doi: 10.1016/j.respol.2013.05.008.
11. Demers-Payette O, Lehoux P, Daudelin Gv. Responsible research and innovation: A productive model for the future of medical innovation. *J Responsib Innov*. 2016;3(3):188-208. doi: 10.1080/23299460.2016.1256659.
12. Wolbring G, Diep L. Cognitive/neuroenhancement through an ability studies lens. In: Jotterand F, Dubljevic V, editors. *Cognitive enhancement: Ethical and policy implications in international perspectives*. Oxford: Oxford Press; 2016. p. 57-75.
13. Blain-Moraes S, Schaff R, Gruis KL, et al. Barriers to and mediators of brain-computer interface user acceptance: focus group findings. *Ergonomics*. 2012;55(5):516-25. doi: 10.1080/00140139.2012.661082.
14. Widge AS, Dougherty DD, Moritz CT. Affective brain-computer interfaces as enabling technology for responsive psychiatric stimulation. *Brain-Computer Interfaces*. 2014;1(2):126-136.
15. Mikołajewska E, Mikołajewski D. Neuroprostheses for increasing disabled patients' mobility and control. *Adv Clin Exp Med*. 2012;21(2):263-72.
16. Brumberg JS, Pitt KM, Mantie-Kozłowski A, et al. Brain-computer interfaces for augmentative and alternative communication: A tutorial. *Am J Speech-Lang Pathol*. 2018;27(1):1-12. doi: 10.1044/2017_AJSLP-16-0244.
17. World Health Organization, World Bank. *World report on disability*. Geneva, Switzerland: World Health Organization; 2011.
18. Kielhofner G. Rethinking disability and what to do about it: disability studies and its implications for occupational therapy. *Am J Occup Therapy*. 2005;59(5):487-96.
19. Imrie R. Rethinking the relationships between disability, rehabilitation, and society. *Dis Rehabil*. 1997;19(7):263-271. doi: 10.3109/09638289709166537.
20. Praestegaard J, Gard G. Ethical issues in physiotherapy - Reflected from the perspective of physiotherapists in private practice. *Physiother Theory Pract*. 2013;29(2):96-112. doi: 10.3109/09593985.2012.700388.
21. Drolet MJ, Désormeaux-Moreau M. The values of occupational therapy: Perceptions of occupational therapists in Quebec. *Scandinavian J Occup Therapy*. 2016;23(4):272-85. doi: 10.3109/11038128.2015.1082623.
22. *Advocacy 2018 [August 2018]*. Available from: <https://physiotherapy.ca/advocacy>

23. Grady AP. Building Inclusive Community: A Challenge for Occupational Therapy - 1994 Eleanor Clarke Slagle Lecture. *Am J Occup Therapy*. 1995;49(4):300.
24. Kostanjsek N. Use of The International Classification of Functioning, Disability and Health (ICF) as a conceptual framework and common language for disability statistics and health information systems. *BMC Pub Health*. 2011;11(suppl 4): S3.
DOI:10.1186/1471-2458-11-S4-S3
25. Roush SE, Sharby N. Disability reconsidered: the paradox of physical therapy. *Phys Therapy*. 2011;91(12):1715-27. doi: 10.2522/ptj.20100389.
26. Poulis I. Bioethics and physiotherapy. *J Med Ethics*. 2007;33: 435-436.
DOI:10.1136/jme.2007.021139
27. Delany CM, Edwards I, Jensen GM, et al. Closing the gap between ethics knowledge and practice through active engagement: an applied model of physical therapy ethics. *Phys Therapy*. 2010;90(7):1068-78. doi: 10.2522/ptj.20090379.
28. Sullivan LS, Klein E, Brown T, et al. Keeping disability in mind: A case study in implantable brain-computer interface research. *Sci Eng Ethics*. 2018;24(2):479-504. doi: 10.1007/s11948-017-9928-9.
29. Rose NS. *Politics of life itself : Biomedicine, power, and subjectivity in the twenty-first century*. Princeton: Princeton University Press; 2007.
30. Phelan SK, Wright V, Gibson BE. Representations of disability and normality in rehabilitation technology promotional materials. *Dis Rehabil*. 2014;36(24):2072-2079.
doi: 10.3109/09638288.2014.891055.