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The art of medicine

Imagining technologies for disability futures

Imagining futures for disabled people is frequently seen in terms of technological change. For example, in September 2019, the Royal Society published *iHuman: Blurring lines between man and machine*, a report that examined the potential of innovative neural and brain–computer interface technologies. Although science will drive such technological developments, it is the ways in which such developments interact with cultural imagination and social realities that animate broader ideas of future bodies and minds. For people with disabilities, this can be a complex and often wearisome process. Excitement about the potential of technology and treatments is tempered by issues such as access, prohibitive costs, and the demands of consultation and assessment. Just a few months before the Royal Society report, journalist Frances Ryan published *Crippled: Austerity and the Demonization of Disabled People*. In her study, Ryan outlined a very different idea of disability futures, noting that “the active, deliberate and persistent maltreatment of Britain’s disabled people has gone beyond critical levels”. For Ryan, the future is one not of gleaming biohybrids, but cuts to services and a lack of technological development. The technologies to come may well be in the realm of the marvellous, but disability experiences are frequently everyday encounters with barriers to inclusion and inadequate access to basic assistive technology. These problems are even more pronounced in low- and middle-income countries where health services may be constrained.

Thinking about how relationships between technology and disability will develop in the future requires attention to all these factors. Imaginings about future technologies and adapted bodies have belonged primarily to fiction, such as Isaac Asimov’s *Robot* series of novels, William Gibson’s cyberpunk, and countless other examples from science fiction, or the tradition of cinematic representation from *Metropolis* through *Robocop* to *Ex Machina*. But the potential of future technologies in this area are found equally in engineering and product development laboratories or in care settings pioneering the use of assistive robotics, for example. Science imagines technology even as it produces it and this imagination—as much as fiction—creates ideas of what a future adapted bodies might be.

With its depiction of reproduction guided by technology, Aldous Huxley’s dystopian *Brave New World* has influenced the imagination of one possible future: the artificial womb. Two research teams are investigating prototypes of artificial womb technologies. Researchers at the Children’s Hospital of Philadelphia created an extra-uterine device or “Biobag” that physiologically supported premature fetal lambs for up to 4 weeks. The Perinatal Life Support project, coordinated by the Eindhoven University of Technology, is developing a perinatal life support system with the aim of potentially providing premature infants with a supply of oxygen and nutrients through the umbilical cord and an artificial placenta. Such research aims to address premature infant

death or the neurological or developmental complications that can be an outcome of extreme prematurity. These technologies are seen by some as potential precursors to full ectogenesis.

Although full ectogenesis remains possible only in the realm of speculative fiction, it is worth considering the connotations of ableism in relation to such technologies. The potential curative aims of these future technologies are bound up with political questions about which lives are worth living, and which lives are valued within society. Not only do the potential outcomes of ectogenetic intervention require interrogation, but the motivations and assumptions driving such technological development demand equally informed, sustained examination.

The ubiquity of references to *Brave New World* in media reports about the Biobag and the Perinatal Life Support are reminders of the role that imagining plays in anticipating, shaping, challenging, and even prohibiting the development and reception of biotechnologies. Speculative and science fiction like Huxley's novel act as testing grounds, allowing creators and audiences alike to experiment with prediction and critique. As science fiction writer Nancy Kress puts it, "In the world's laboratories, science rehearses advances in theory and application. In fiction, SF writers rehearse the human implications of those advances." In her view, "science fiction is the dress rehearsal for social change". The connections made in the media between *Brave New World* and ectogenesis projects tend to overlook the contextual particularities of Huxley's depiction, which portrayed artificial wombs as eugenic technologies that facilitate the hierarchical classification of society. Science fiction like Huxley's can help elucidate the promises and perils of these technologies, and the ethical questions that arise in their use, including often invisibilised questions and assumptions concerning ableism.

Issues of implicit ableism also affect another application of brain-computer interface technologies: augmented communication. A dominant narrative around the future of augmented communication is that of implantable brain to speech prostheses. The ultimate promise here is speech "at the speed of thought", for all that the technology is at a preliminary stage. But is this the best way to understand what disabled users want from such technologies? In his book *Meaning of a Disability*, the ethnomethodologist Albert Robillard examined the lived experience of the progression of his own motor neuron disease. The disabling aspect of not being able to speak, he noted, was not only that he could not be heard, but that "I cannot talk or communicate in anything approaching the social consensus of 'real time'". Yet Robillard himself was sceptical of, even resistant to, attempts to "cure" his communication problems with technology—"I do not know how many times I have been told, jokingly or not, 'We are going to make you into a bionic man.'" His account explores how manifestations of his disability are more complex than just the restoration of speech.

The development of brain-computer technologies will continue yet should not preclude the development of alternative futures. Such alternatives are important because the lived experience of disability continues in the meantime, and lives will be lived before new technologies are perfected. Even then, because of the economics of disability, such technologies will not be available to all. Robillard writes that "the constant barrage of requests to purchase assistive equipment to help yourself and your family

makes you feel inadequate at first for not having the necessary funds. This feeling of inadequacy quickly turns to anger.” For some disabled people, the ideal might not be to fit into normative communication, but to mutually establish different meaningful interactions with their conversational partners. This issue is most obviously in need of being directed by the stances of disabled people themselves, as co-researchers. Writer and scholar Lateef McLeod, who also uses augmented communication, is clear in his poem *I Am Alright*: “I don’t need a doctor to come up with a cure”. Another user of augmented communication, Colin Portnuff, invited researchers “who are engaged in the science of speech and voice development to adopt as your mentor a person or community with impaired speech.” He urged them to “Spend time with us. Learn from us, and teach us.” Imagining alternative futures for augmented communication itself involves challenges in communication and imagination.

Understanding the range of issues disabled users actually face is complex and testing, which is precisely why participatory research, collaboration, and co-design are called for. The issue of imagining arises constantly in the development of products and new technologies that are designed to engage with the priorities and needs of disabled people. Although much of the day-to-day work of product development is focused on prosaic issues of problem-solving and refinement, broader questions of which problems get tackled and what goals technologies are developed to fulfil are matters of additional abstraction. This is reflected in Peter Kroes and Anthonie Meijers’ philosophy of technology concept of the “dual nature of technical artefacts”: that created objects have both a physical nature, and an intentional nature. They are not merely a result of systematic problem-solving, but of intent and purpose. The question then arises: whose intent? Whose imaginings and priorities feed into the cycle of ideation and evaluation that makes up the design process?

To address these concerns, user-centred design approaches aim to ensure that developments are reviewed with users and accurately reflect those users’ needs. In co-design, users are invited into the development process so that their contributions can help to shape the product. In the context of disability, this raises further questions of exclusion. Are disabled users themselves considered partners in the development process? Or are they only represented by proxy through carers, clinicians, and other experts? As disabled designer Liz Jackson has observed: “Disabled people have long been integral to design processes”, but “our contributions are often overshadowed or misrepresented”. There are also tensions that arise when users are seen as a burden on innovation, unable to imagine potential new technologies in the way that those closely involved with those technologies might. Perhaps the question that needs to be addressed is how disabled people can be brought together fruitfully with technologists to jointly imagine the future? And to do this requires understanding how the complexities of cultural and social imagination work more broadly—in narrative, image, and personal reflection. If we pause to dial down the celebration of the biohybrid technologised body and rather focus on everyday experience and the opportunities for broad discussions of product development, we may find disability futures that are more inclusive, effective, and just.

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