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The Art of Medicine

Imagining Technologies for Disability Futures

The future of disabled people is frequently seen in terms of technological change, especially developments that will make improvements in treatment and lived experience. As an example, in September 2019, the Royal Society published *iHuman perspectives: Neural Interfaces*, a report that summarised the potential of innovative brain-computer interface technologies. It noted applications that include post-surgery recovery, ‘typing by brain’, uses of a ‘mental mouse’ to control computers and devices, augmented communication technologies, as well as wider uses for conditions such as Alzheimer’s Disease and those associated with mental ill-health.

For all that it is science that will drive technologies such as neural interfaces, it is the ways in which technological developments interact with cultural imagination and social reality that animate broader ideas of future bodies and minds. For those with disabilities, this can be a complex and often wearisome process. Excitement about possible treatments is tempered by issues such as access, prohibitive costs and the demands of consultation and assessment, and it was no coincidence that 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 are limited and rights go unrecognised.

Thinking about how relationships between technology and disability will develop in the future requires attention to all these factors. It might seem obvious that the imagination of future technologies and adapted bodies belongs primarily to fiction – Isaac Asimov’s robots, 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 such processes 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 disabled body might be.

With its depiction of reproduction guided by technology, Aldous Huxley’s *A Brave New World* has played a formative role in the imagination of a very particular future, one that might not immediately seem relevant to disability futures: the artificial womb. At present, two research teams are currently at work prototyping artificial womb technologies: researchers at the Children’s Hospital of Philadelphia have created the ‘Biobag’, which successfully gestated a lamb for 4 weeks in 2017; and the ‘Perinatal Life Support’ project in Eindhoven is developing what they have dubbed an ‘artificial womb’ which would provide premature infants with a supply of oxygen and nutrients via an artificial placenta. Both projects are aimed at preventing premature infant death and neurological or developmental disabilities that can be an outcome of extreme prematurity. These technologies are often seen as precursors to full ecotogenesis - reproduction and gestation, from conception to birth, outside the human body.

While full ectogenesis remains possible only in the realm of speculative fiction it is worth considering the connotations of ableism within such ‘artificial womb’ technologies, which are frequently framed as dispellers of disability. The curative aims of artificial womb technologies are bound up with political questions about which lives are worth living, and which lives are valued within society. Like many technologies promising the creation of healthier, less disabled, more caring futures, the discourse around artificial wombs relies on the transparency of key terms – health, disability, care – that are in fact highly contentious, and ethically and politically fraught. 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 Nancy Kress suggests, "abstract debate about" science and technology fails to grasp fully how it affects people; by telling its materially-situated stories, science fiction can serve as a necessary supplement to the public culture of scientific development; as 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” (207). The connections scientists and journalists draw between *Brave New World* and current ectogenesis projects tend to overlook the contextual particularities of Huxley’s depiction, which treats artificial wombs as eugenic technologies that facilitate the hierarchical classification of society. Science fiction like Huxley’s, when read closely can help elucidate the promises and perils of medical technologies like artificial wombs, and the complex ethical questions that arise in their use, including often invisibilized questions and assumptions concerning ableism.

Issues of implicit ableism also affect another application of brain-computer interface technologies: augmented communication, which includes the kind of text-to-speech devices publicly associated with physicist Stephen Hawking and comedian Lee Ridley. The dominant narrative around the future of augmented communication is that of implantable brain to speech prostheses, early clinical development of which is already underway in San Francisco. The ultimate promise here is speech ‘at the speed of thought’, for all that the technology is in its very early stages.

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 just that he couldn't be heard, but that “I cannot talk or communicate in anything approaching the social consensus of ‘real time’.” This goes beyond communication itself being slower: communication partners are difficult to engage; conversations challenging to initiate, maintain and, if necessary, repair. 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.’” – seeing the manifestations of his disability as 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. The value of such alternatives is clear for a variety of reasons: because the lived experience of disability continues in the meantime, lives will be lived before new technologies are perfected. Because of the economics of disability, new 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 last 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 influential 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.” His choice of the word ‘mentors’ frames a very different relationship than as patients, clinical subjects or case studies. “Spend time with us. Learn from us, and teach us.”

Imagining alternative futures for augmented communication itself involves challenges in communication and imagination. Brain to speech interfaces may be technically and clinically audacious but are in some ways easier to imagine than less technological ‘advanced’ counterparts. In the way that the devices supposedly 'disappear', for example, the wearer/user appears to be restored as a natural speaker (natural and restored both being contentious terms). Imagining the range of issues disabled users actually face is more 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. While much of the day-to-day work of product development is focussed 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 feed into the cycle of ideation and evaluation that makes up the design process?

To address this, 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 contribution 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 though 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 technologized 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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