Exploring the Crip Politics of Biomedical Technologies

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For more on this project, including citations: _Account/Ability: Disability and Agency in the Age of Biomedicalization._

Image Descriptions

Each slide features a border of three pictures.

- An x-ray image of deep brain stimulation recipient from the chest up. Visible on the x-ray is the power pack, located just above the sternum and two electrodes in the brain.
- A colorized karyotype of Trisomy 21. Showing pairs of chromosomes lined up largest to smallest.
- A hand holding an artificial pancreas rig with two circuit boards. One is rubber banded to another piece of tech.

Depending which technology is being discussed, one of the images will be in full color while the others are faded.

Slide 1

- In late 2018, I met Mary, a middle-aged woman living in the Southwest United States, to talk about brain implants. Mary was an author, writing about her experiences with early-onset Parkinson's disease. In 2012, she received a deep brain stimulator, which sends electrical impulses to the areas of her brain that control things like gait, balance, and tremor. While she is pleased with her implant overall, she (and her husband Barry, who joined us for the discussion) also expressed disbelief at the disconnect she felt designers and clinicians had from disabled people for whom these devices were intended. For example, her implant is powered by a battery pack that sits at just under her clavicle. The device has a squared edge that juts out, meaning she is now unable to shave her armpits, a fact that has impacted her self-image.
- Near the end of our conversation, she also shared her thoughts on a new device in development. The design was for a controller that allowed the user to adjust the level of stimulation from the implant within certain pre-determined parameters. Whereas previous models using analog buttons, this new design featured a sleek touch screen.
- While in line with current tech trends broadly, Mary and her husband rolled their eyes at the new design. For many people with Parkinson's, tremors and fine motor dexterity issues means that touch screens are difficult, if not impossible to use. The irony was palpable: a piece of technology that's sole function was to enable user control over their medical device was useless to many of its intended users.

Slide 2

- As Barry said, "If they had talked to the patient first, they would've pointed that out right away. You're going in the wrong direction here. People with Parkinson's should be the ones who are designing these things." This story is indicative of the two intertwined tensions I want to explore today – the presumption of personal responsibility in managing disability, and the invalidation or dismissal of embodied experience in favor of clinical, medical, and technological expertise

Slide 3

- Many technologies used in medical care are developed and marketed as providing individual users with new kinds of knowledge – such as genetic tests – or autonomy and independence – such as exoskeletons. With this increased use comes a subtle but insidious assumption that having more and more advanced technology results in better and more just societies, in part through the production of perfectly independent, perfectly self-governing, perfectly productive citizens. A kind of techno-optimism, this idea assumes that the sole reason we are not living in a utopian ideal is that we aren't using the right tech yet. People with non-normative bodyminds face social, political, and material pressure to intervene on their bodyminds to closer approximate the norm – in other words, to redeem their disabled selves through human-machine hybridity.
- Today, I want to use stories I have gathered from users of three biomedical technologies to explore the promises made about these human machine hybrids – and how they square with actual lived experiences.

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- The three technologies are deep brain stimulation, prenatal genetic testing, and do-it-yourself artificial pancreas systems as created by communities with Type 1 diabetes. I have written and presented on each of these case studies separately, but am now working to draw them together meaningfully. In placing these seemingly disparate technologies side-by-side, I hope to shift away from this mindset that views each new innovation as exceptional and instead recognize the commonalities in their design practices and discourses.
- By collecting narratives from users of these technologies, I explore the discourses embedded in medical technologies and that articulate the spaces in which they're used. I do want to quickly attend to the fact that "user" in all of these cases is *not* synonymous with "disabled person" – prospective parents using prenatal testing, for example, and a guardian managing DIY APS systems for their often very young children. The politics of these interactions are different in significant ways from users who are themselves disabled – a fact I am exploring in more detail in my current book project. But for the sake of today's arguments, the promises made through biomedical tech appear across these scenarios.

Slide 5

- I frame them as promises, each rooted in what Ashley Shew dubs technoableism, or "a rhetoric of disability that at once talks about empowering disabled people through technologies while at the same time reinforcing ableist tropes about what bodyminds are good to have and who

counts as worthy." To illustrate these promises, I present excerpts from over 40 interviews conducted with users of the three technologies.

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- The first promise is Self-Responsibility
- This is a familiar narrative, both in medical technology and in technology writ large – use this tech and achieve independence. From Google maps to robots for elder care, the promise of technologically-enabled self-sufficiency reveals a societal fear of dependence.
- Alongside this narrative come a subtle but critical shift in accountability. The management of misfitting bodyminds is not in this context public responsibility, but an individual one.

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- There is an important distinction, however, from a strictly privatized and individualized understanding of disability – a difference that is cemented and perpetuated through what Dan Goodley dubs "neoliberal ableism," which suggests there are "increased expectations placed on the autonomy of self-responsible individual citizens to care, educate and govern themselves" (2014, 63)

Slide 8

- For example, drawn from narratives I have collected from recipients of deep brain stimulation. John, a 75-year-old living in Northern California, is candid about his choice to pursue the brain implant, saying, "I needed to lighted the load, which has not been terribly lightened, but I needed to lighten the load of my lovely caregiver wife, who I owe everything to…it's one of those difficult things, where you know you're a burden but you don't know what to do about it."
- This neoliberal self-responsibility also appeared in interviews conducted with prospective parents choosing prenatal genetic screening and testing. For many prospective parents, testing and screening was seen as an obligatory expression of responsibility. Professionals conceded that even though they insist testing is optional, many prospective parents feel coerced or beholden to the authority of their clinicians or judgement from those around them.

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- For example, Abby (p. parent), whose religious beliefs initially dissuaded her from receiving NIPT, eventually changed her mind, stating, "I had to prove that I'm going to do everything I can if it's going to be something wrong or whatever." She felt compelled to "prove" her fitness for motherhood, and implicitly linked preparedness with the knowledge accumulation that comes from genetic screening.

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- The Promise of Knowledge
- Technologies that quantify and visualize bodyminds – from karyotypes to glucose monitors to step counters – transform and reduce the holistic experience of embodiment to a calculable one. Embodiment can be measured and deemed in-range or out-of-range, normal or abnormal. The accumulation of data, regardless of its intrinsic value or the often blackboxed algorithms

that give it with meaning, becomes synonymous with the accumulation of knowledge. And the accumulation of knowledge is interpreted as imperative for thinking and acting as a responsible neoliberal subject. Many informants who used PGS/PGD perceived some kind of knowledge from screening and testing as necessary for responsible parenting.

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- For example, prospective parent Patsy shared, "I just figured knowledge is power and we might as well know what we're dealing with." (Patsy, p. parent).
- Knowing "too much," however, which often meant seeking more information than the clinician recommended was considered in some way reckless, exacerbating unnecessarily feelings anxiety and responsibility rather than mitigate them. Knowledge, through datafication, became a pathway to self-responsibility, but the limits to what was allowable to know were clearly defined within the parameters of clinical authority.

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- Which leads to the third promise, Control.
- For many users of deep brain stimulation, the implant was explicitly presented to them as a means of recapturing or retaining control over a bodymind made unruly through acquired disability. Disability was sometimes perceived as invasion, loss of control, or movement away from an idealized self.

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- Hospital information sheets often used phrasing such as "Don't let tremors control your life" and made references to the observable dimensions of a condition being "embarrass[ing]" or "emotionally traumatiz[ing]." Deep brain stimulation and knowledge acquisition through visualization techniques such as MRIs are means of control.
- This control, however, comes with contingencies. The first comes in the form of the technology itself. DBS has a wide range of applications, but in all cases serves as a means of symptom-management rather than treatment of the underlying condition. Therefore, in the design and application of DBS certain symptoms emerge as important and in need of management, while others do not. What gets considered significant, what is measurable, and what aspects of disability are in need of management are all unsettled in the case of DBS – resulting in a mismatch in priorities and expectations between disabled people and technologists and clinicians. For example, one interviewee revealed that no clinician had ever mentioned that Parkinson's disease could be painful, instead only discussing visually apparent symptoms like tremor that could be mitigated through implants.

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- For people with Type 1 diabetes, the promise of control enabled through the datafication of bodyminds – continuous glucose monitors and insulin pumps – is accompanied by blame when health outcomes fall short of expectations. Carolyn, who has been living with Type 1 diabetes for over 50 years, shared her frustration with the blame experienced by many people with T1D,

which she suggested often fails to account for the cognitive, physical, and emotional toll constant management can take on a person:

- "And, yes, they are blamed. And even if they're not doing everything they should and could be doing, they're not evil people. They're just burned out. They're tired. They're overwhelmed by it. And how do you keep doing the same thing, and not getting good results, and keep caring to do it?"
- However, those who assert control through DIY diabetes technologies such as APS – which both shift some of the cognitive burden of constant decision-making onto the technology rather than the person and which early evidence suggests maintains much more consistent results than traditional methods – these users are not celebrated for their self-sufficiency and self-responsibility, as you might expect, but accused of transgressions of authority that disrupt and supplant medical authority.

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- The final promise – or perhaps the primal promise – of biomedical technology is the promise of cure. This promise subsumes and swallows whole the other promises of biomedical technology, displacing interest, urgency, and funding for technologies contributing to maintenance, comfort, and quality of life in favor of a curative future without disability at all.
- Members of the DIY diabetes community often coalesced around a frustration with mainstream and sanctioned diabetes technologies, which were often described as having stagnated or otherwise completely fail to address many of the daily needs and desires of diabetic people. Many chafed against the mismatched priorities that resulted in sanctioned technologies and treatments that did not work as desired.

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- While diabetics and their families looked for strategies, practices and technologies to improve their quality of life, they receive instead promises of an imminent cure. Many, like Evelyn (a DIY user in her mid-50s), remarked on the humor of being told over their entire lifetimes that a cure was coming: "everything's always five years away."
- Carolyn was adamant about the danger of a curative promise, noting that this rhetoric sells a version of diabetes that doesn't require daily management. She recalls her diagnosis over 50 years ago, which was accompanied by her physician's promise of a forthcoming cure in two, five, ten years. She grapples with having to give up on that curative promise in order to instead focus on survival

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- In fact, as revealed by Gordon, a member of the DIY community through the management of his young daughter's diabetes, the recognition and rejection of the curative promise is key to the formation and cohesion of the DIY community: "I mean, even just this insight of like, the shift from quality of life to cure, I think is really critical. Because cure is so inaccessible, like it's the specialized guild and priesthood of medicine that has all these boundaries around it that you can't cross."

- In his estimation, this curative promise keeps control and authority firmly in the hands of clinicians and researchers, while quality of life thinking delegates agency back onto individuals whose lived experience is essential for meaningful design and practice in this space.

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- Rhetorics of individual agency and independence mobilize discourses around the development and use of biomedical technologies, and yet feelings of guilt, personal responsibility, and limited options are often expressed as driving the decision to use them. These encounters, however, cannot be considered in isolation. The experience of biomedical technologies exists at the interface of bodymind and environment, but it also exists at the interface between self and community, human and technology, discourse and materiality. Ignoring the complexities that frame the individual experience of biomedical technologies obscures the sociality embedded in technological interventions to begin with. So thinking in those contexts, what happens when technological innovation is resituated not to ameliorate the bodymind-environment disjunction via the bodymind, but to address the causes of neoliberal ableism at their root? This is where I see spaces opening up to create alternative imaginaries for inclusive futures.

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