OPINION: The future of assistive tech is surprisingly simple

Everyday technologies that enhance accessibility are far more helpful than miraculous, high-tech interventions

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On July 20, Alice Wong, the founder of the Disability Visibility Project, went to the White House celebration of the 25th anniversary of the Americans with Disabilities Act. She mingled. She saw friends and they took selfies. She got a picture with the president. Throughout, Wong, a wheelchair user who doesn’t travel, was sitting in her California home, using BeamPro software to connect to a Telepresence device in the East Room. With the help of some friends in D.C. and relatively simple modern communications technology, Wong could travel, in her own words, as a “cyborg.”

The news media and tech industry love a good disability miracle story. Cures, recoveries, robot limbs, wonder drugs and other seemingly magical innovations capture our imagination and predict a world without illness, impairment or disability. But the brightest future of assistive technology — a catchall term for any hardware or software used to “increase, maintain or improve the functional capabilities of individuals with disabilities,” according to the Assistive Technology Industry Association — will not be found in such marvelous manifestations. Rather, it will be in the application of everyday technology to enhance accessibility and fight stigma.

Here’s the kind of story that dominates the news: The “medical miracle” of an exoskeleton that enabled a young paraplegic man to walk kicked off the 2014 World Cup. A YouTube video proclaiming, “Miracle!! Deaf Boy Hears Father’s Voice for the First Time,” has 5.7 million views, and there are countless others just like it. Recently, “Bionic eyes” have generated headlines proclaiming, “It’s a miracle!” A stair-climbing wheelchair could make “the world more accessible for everyone!”

Potential cures for disabilities are almost as exciting as cool tech devices. Pharmaceutical companies frequently tout potential cures for Down syndrome. Americans donate millions of dollars to Autism Speaks’ quest for a cure. Our love of cures has enabled a whole industry of snake-oil peddlers who advocate putting autistic children on strange diets or giving them bleach enemas. In all these stories, the focus is on changing the individual to adapt to an inaccessible or neurotypical world.

The documentary “Fixed: The Science/Fiction of Human Enhancement,” which has been airing this summer on public television (click here for listings), gives ample space to technologists, futurists and wildly optimistic dreamers about the future of disability and human capacity. A paralyzed man uses a robotic arm controlled by his mind to hold his girlfriends’ hand for the first time. Hugh Herr, a double
amputee of the legs, says that with his prostheses, he is a better mountain climber than he was before his accident. Fernanda Castelo serves as a test “pilot” for Ekso Bionics, using an exoskeleton to take her first steps since she became a paraplegic. The transhumanist James Hughes argues for enhancing the human species and eliminating neurodiversity, saying that while children with Down syndrome might have some special gifts, “If you want to just have a child to enrich your family, why don’t you get a dog?”

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Sara Hendren
Assistant Professor, Olin College of Engineering

Regan Brashear, the filmmaker, told me that she wanted to explore “an underlying disconnect about how people are perceiving disability”:

Is it a valuable part of human life that will always be with us, or is it a problem to be fixed or eliminated? These perspectives lead us towards very different futures. One is about fighting for inclusion on all levels of society, ending stigma and developing useful and needed assistive technologies to enhance quality of life in conversation with the intended users. The other perceives disability as an inherent negative to be “fixed” at all costs.

The film, she hopes, helps us address the really basic question, “What is the problem that needs fixing?”

To explore this disconnect, Brashear sets these celebratory futurists against people who don’t believe they need fixing or high-tech interventions. She centers much of the film on Gregor Wolbring, an “ability studies” scholar who personally models the simple technologies and accommodations a person with disabilities requires to be a full member of society. He uses a wheelchair, likes to crawl and gets around fine with little help. He criticizes the transhumanist movement for its emphasis on ability and productivity. In another scene, activist and wheelchair user Patty Berne points out that all the fancy innovations in wheelchair design (such as stair-climbing) sound good, but who is going to pay for it? Who will fix it? We see her stuck, calling for repairs, when her chair breaks down. Instead, she suggests a simpler priority for wheelchair-makers: to develop a widely available chair that’s waterproof.

Brashear intersperses interview footage with dance performances featuring people with disabilities, offering a wordless, but powerful, rebuke to the notion that such bodies necessarily need fixing. She isn’t opposed to technological innovation, but she wants to “ensure that these innovations are helping to shape the kind of world we want to live in.”

Innovation is coming. Google, for example, just launched the Google Impact Challenge: Disabilities, a $20 million commitment that, according to Meghan Casserly, spokeswoman for Google.org, “asks
nonprofits around the world to share their plans to improve access and independence for people with disabilities.” (Full disclosure: I consulted, helped write and conducted interviews for a related project in which Google commemorated the ADA.) In its call for ideas, it asks, “What if we could work together to identify the biggest barriers people with disabilities face and help create ways to solve them?” This is the kind of approach that needs to be replicated more broadly, as it focuses on ameliorating barriers rather than fixing people.

Sara Hendren, an assistant professor of design at Olin College of Engineering and an expert in assistive tech, told me, “It’s only now that there’s enough political momentum for people with disabilities to make unignorable, very public statements about their identities as a variation of normalcy — not necessarily a medicalized disorder.” I’m not sure I share her optimism about such statements being unignorable. The transhumanist ideology and the breathless media pursuit of feel-good “miracle” stories feeds our “ableist” culture, telling us that non-compliant minds and bodies need to be fixed or normalized.

Against that, we have Alice Wong at the White House, a building made more accessible through a relatively simple piece of software and a fancy robot. These are the kinds of technologies we need to bring to scale by applying already extant technologies to enhance accessibility. When we remove barriers and fight stigma, we can fix what needs fixing — society.

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