THE GIRL WITH THE SERPENTINE ARM
Casey Shearer Memorial Award for Excellence in Creative Nonfiction
Stephanie Hayes B'15

Jo-Jo Cranfield stares seductively at the camera as a 12-foot long python wraps itself around her lounging, bikini-clad body. A second, smaller snake loops itself in tidy coils around her left forearm. Its red-speckled skin matches Cranfield's scarlet fingernails and pillar-box red bob. Its thin tail pierces the underside of her wrist and slides into her flesh, a surreal needle and thread.

The first snake is real. The second, and the forearm it's draped around, are made of silicon. You see, Jo-Jo Cranfield is a congenital amputee, born without a left forearm or elbow. Given a new government-funded limb every few years since birth, Cranfield—now 21—has amassed quite the collection of plastic arms. Each arm aimed for inconspicuousness, but with immovable plastic fingers and slightly mismatched "skin" coloring, each arm failed. One by one, they were consigned to a box beneath Cranfield's bed, unworn.

This limb, designed and photographed by The Alternative Limb Project, is the first she's opted to wear. Slithering up and down her arm, it proudly flaunts its artificiality.

Jo-Jo Cranfield wearing her Snake Arm
Photo courtesy of The Alternative Limb Project

The London-based Alternative Limb Project is at the forefront of innovative prosthetic design, creating bold, bespoke limbs for amputees. After earning her degree in Filmic Special Effects, the studio's founder, Sophie de Oliveira Barata, spent eight years making realistic-looking limbs for a major prosthetics provider before starting her own studio. Although she continues to craft realistic appendages from silicon, what sets her studio apart are her "alternative limbs." These slot into two categories: "surreal limbs" and "unreal limbs." Surreal limbs combine realism with dream-like elements—picture a henna tattoo arm whose pattern never fades, a shoulder erupting with bird feathers, or bionic components set into skin. Her unreal limbs barely resemble natural appendages and instead emphasize graphics, unusual textures, or pieces of technology. Imagine a leather arm with pocket knife gadgets tucked inside the fingers, a Japanese vase come to life as a leg, or a leg layered with drawers to store a girl's stickers, pens, and glitter.

British performing artist, Viktoria Modesta, is the proud owner of one such unreal limb, called "Stereo Leg." This leather-coated, below-knee leg is fitted with a set of speakers and adorned with crystals. The leg's titanium pole is exposed and ornamented with even more bling. In photographs, Modesta wears the leg with a futuristic plastic dress, patent leather heels, and a voluminous up-do.

"The first time I wore a limb that was so obviously BIONIC, it gave me a total sense of uniqueness...of [being a] mutant human in the best way possible," writes Modesta, in a testimony on The Alternative Limb Project's website. "The ideas [people] have of what an amputee might look like or act like are, in most cases, negative. So when they clock my appearance and see the leg, it's very challenging for them."

These bold limbs convert prosthetics limbs into an accessory, a chance to distinguish oneself in a positive way. But they remain a rarity.

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"The priority for design for disability," writes Graham Pullin, in *Design Meets Disability*, "has traditionally been to enable, while attracting as little attention as possible." With the exception of glasses, this priority holds largely true today. Hearing aids are molded from colored plastic to blend in with the wearer's skin, while wheelchairs have adopted many practical features of mountain bikes, but remain largely uninfluenced by the dynamic world of chair design.

When it comes to prosthetic limbs, the dominant thinking is that a new limb should resemble the absent limb as closely as possible. It should, so conventional wisdom holds, realistically mirror both the movement and appearance of a natural limb. It should be as inconspicuous as possible.

In recent years, prosthetic limbs have made great advances towards realism, with the birth of bionic limbs and the development of prosthetic leg covers that approximate the look of skin. Despite these advances, no prosthetic on the market today can simultaneously achieve both natural movement and a realistic appearance. Prosthetic design remains a tug-o-war between form and functionality, with advances in either direction causing losses to the other.

Even the highest quality limbs face this dilemma. Sophie de Oliveira Barata's realistic limbs resemble natural appendages down to the last freckle, wrinkle, and faint half-moon on the surface of the fingernail. Her painstaking process includes plucking hairs from the back of her patients' necks to add to their prosthetic toes and crafting bunions out of silicon. The resulting sense of realism fades, however, when the limbs are in motion, as most have fixed wrists and immovable digits.

Sophie de Oliveira Barata in her studio
Photo courtesy of The Alternative Limb Project

Similar limitations apply to bionic limbs. Take the DEKA arm system, which received approval from the U.S. Food and Drug Administration in May 2014, and is at the cutting edge of prosthetic design. Roughly the size and weight of a natural adult arm, it has sensors that detect electrical activity in the amputee's remaining chest muscles and send signals to the arm, which responds by opening or closing the hand. Using this bionic arm, veterans who participated in clinical trials were able to perform dexterous tasks with relative ease. But, with its white plastic coating and clunky appearance, it resembles the appendage of a Lego man.

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Don't stare!–Everybody's mother
—"Staring at the Other," Rosemarie Garland-Thomson

Western society reserves a special kind of look for the disabled body: the stare. "A more forceful and sustained form of looking than glancing, glimpsing, scanning, contemplating, surveying, gazing, and other normative forms of looking, staring starkly registers intense interest and endows it with meaning," writes Rosemarie Garland-Thomson in "Staring at the Other."

The stare, however, is strictly policed. "The one thing everyone knows about staring is that your mother told you not to do it," states Garland-Thomson. As a result, Western history is replete with hyperbolic, ritualized displays of odd or "monstrous" bodies; displays that provided a context in which staring was acceptable. In the past, such displays took the form of street fairs, freak shows, and even public executions, explains Garland-Thomson. Today, they occur in the horror film and the tabloids—less overt displays that lack the reciprocity of the live staring encounter. Supposed to be a private, furtive pleasure, in reality staring extends well beyond these bounds.

For many amputees, the stare is expected and never-ending. "You're fresh meat when you're somewhere new," explained below-knee amputee Priscilla Sutton. "I don't really think about it 'til I'm in the street wearing shorts or a skirt and people turn their heads." Sutton's mother becomes highly protective of her when they're out in public together. "I tell her: 'it's okay, Mum. If I didn't want people to stare, I would wear jeans.'"

Prosthetic limbs that attempt invisibility and fail, many amputees told me, only enhance the pitying nature of such stares. As Pullin writes: "There's something undermining about invisibility that fails; a lack of self-confidence that can communicate an implied shame." When it comes to assistive technologies, the desire for invisibility could mean many things: that the wearer doesn't want assumptions being made about their abilities, that they don't want disability to be the main topic of conversation, that they just want privacy. Yet, just as bold glasses suggest confidence, prosthetics that shoot for invisibility and fail are often interpreted as a sign of shyness or shame.

In *Staring*, Garland-Thomson, describes how the stare materializes as a look and a rapid look-away, a registration of difference followed swiftly by a reprimand. The onus, she notes, is then on the "staree" to make the next move. Should they stare back? Should they use their charm, friendliness, or humor to take control of the encounter? "Stareable people have a good deal of work to do to assert their dignity or avoid an uncomfortable situation," Garland-Thomson writes.

Amputees told me that bold prosthetics do much of this work for them, altering the nature of the stare or serving as a kind of return stare. Below-knee amputee and actor Anthony Jennings explained that bold assistive devices completely change the dynamic of the look. "You know, if I see a guy in a wheelchair, I'm going to look," he said. "If I see a guy with a wheelchair that's all chromed out and has *rims* on it, I'm still going to look, but I'm going to think 'Wow, this is awesome!'"

Cranfield explained that her snake-adorned arm stands in place of the stare back. "[Bold prosthetics allow me to] show off, accessorize and let the outside world know 'I'm okay. I'm capable of carrying my bag myself, thank you' It lets people realize that I'm a person who doesn't require anyone's sympathy…even go[es] as far as to say: 'Hey, maybe you should be jealous you're not me...'"

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Perhaps, then, it's time to reconsider the goal of inconspicuousness when it comes to prosthetic limbs. Perhaps it's time to acknowledge that, within the bounds of today's technology, even the highest quality limbs are still conspicuous, and it's only because they are *unintentionally* so that they rarely contribute positively to amputees' sense of self. Perhaps it's time to ask: what might happen if we *aimed* for conspicuousness, flaunted limb difference, and treated prosthetics as fashion accessories?

A possible answer is found in the history of glasses. The only assistive technology to have made the transition from a medical necessity to a fashion accessory, glasses are often cited as the exemplar of design for disability.

Yet, as recently as the 1930s, Britain's National Health Services classified spectacles as a "medical appliance" and dictated that they should not be styled. In the 1960s, British schoolgirls were prescribed transparent pink plastic frames, ambitiously called "invisible frames." It wasn't until the 1970s that the NHS officially acknowledged the importance of styling.

Today, glasses are available in a range of styles and colors, and frames are named after poets, performers, and famous fictional characters. Glasses design has even reached the point where functionality is, sometimes, completely irrelevant. In 2012, a fad swept the National Basketball Association in which dominant, fashion-forward players like LeBron James, Dwayne Wade, and Russell Westbrook donned lens-less specs in post-game interviews.

Importantly, though, glasses don't owe their acceptability to their invisibility. The fact that glasses continue to exist and thrive alongside contact lenses, which offer the chance for complete invisibility, is testament to this. Conversely, the move toward larger, colorful frames and away from transparency is what saw glasses become more acceptable. By allowing wearers to "own" their impairment, bold frames are less stigmatizing than the "invisible" frames pedaled by the NHS.

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Although inconspicuousness didn't improve the public's perception of glasses, bright, decorative frames remain a minority taste, with most spectacles sitting somewhere between "invisible" and bold. Similarly, bold prosthetics are unlikely to appeal to the majority of amputees—nor are they practical or affordable options for most.

When I described Cranfield's snake-adorned arm to the Founder of the New England Amputee Association, Rose Bissonnette, she made a noise of disgust. “I’ve spoken to many arm amputees and I promise you, they want to look as normal as possible,” she said.

From interviews, however, I concluded that it comes down to individual preference. As Cranfield succinctly explained: “[Amputees’] experiences and confidence vary, just like everyone else. For example, one overweight woman may choose to cover herself with clothing to hide her weight, whereas another may choose to embrace her body and wear skimpy dresses.”

Even those individuals who like the idea of wearing bold limbs might not want to wear them all the time. Although bold prosthetics help amputees control the nature of the stare, they don’t cause it to disappear. Sutton explained that, when she’s having a rough day and wants to avoid being stared at or approached by strangers, she wears pants to hide her tattoo-look leg.

Another limit to the spread of bold limbs is practicality. Bling and decoration add weight to prosthetics, making them too heavy for-day-to-day use and relegating them to the status of accessory limbs. Certainly, both Cranfield and Modesta reserve their bold limbs for noteworthy occasions.

Financially, though, a second limb isn’t an option for many amputees, as most struggle to fund a single limb. A study by the Amputee Coalition of America found that the average below-knee and below-elbow prostheses cost $5000-$7000 and $3000-$10,000, respectively. The addition of joints in above-elbow and above-knee prosthetics can double or triple the cost to $10,000-$30,000. More advanced prostheses, such as the “C-leg”—an above-knee leg fitted with microprocessing technology that adjusts to changes in speed and incline—can cost up to $100,000.

Ryan Seary’s “Removable Muscle” Leg
Photo courtesy of The Alternative Limb Project

This immense cost means most patients rely on insurance companies for funding, which, in the United States, is a convoluted system. Funding schemes vary by state and differ wildly between public and private insurers. One consistent factor is that each scheme will only pay for what is absolutely "medically necessary." Medicare, the main prosthetics provider in the U.S., allots funding according to a patient's estimated rehabilitation level, in a system called the Medicare Functional Classification Level. They classify patients according to "K-Levels," which range from Level 0 where "a prosthesis does not enhance the quality of life or mobility," to Level 4, where prosthetic use "exceeds basic walking skills, exhibit[s] high impact, stress or energy levels" Individuals classified as a Level 0 are denied funding. Patients classified as Level 2 or above receive rotating ankle joints, and those designated Level 3 or 4 (typically young people) receive flexible feet and pneumatic knees.

This system means that bold, creative limbs remain firmly outside the scope of insurance funding. Writing for *The Boston Globe*, Scott Kirsner summed up this attitude perfectly: "When someone has lost a limb, Medicare and private insurers would prefer to buy the Kia, not the Tesla, an electric car that sells for $70,000 and up."

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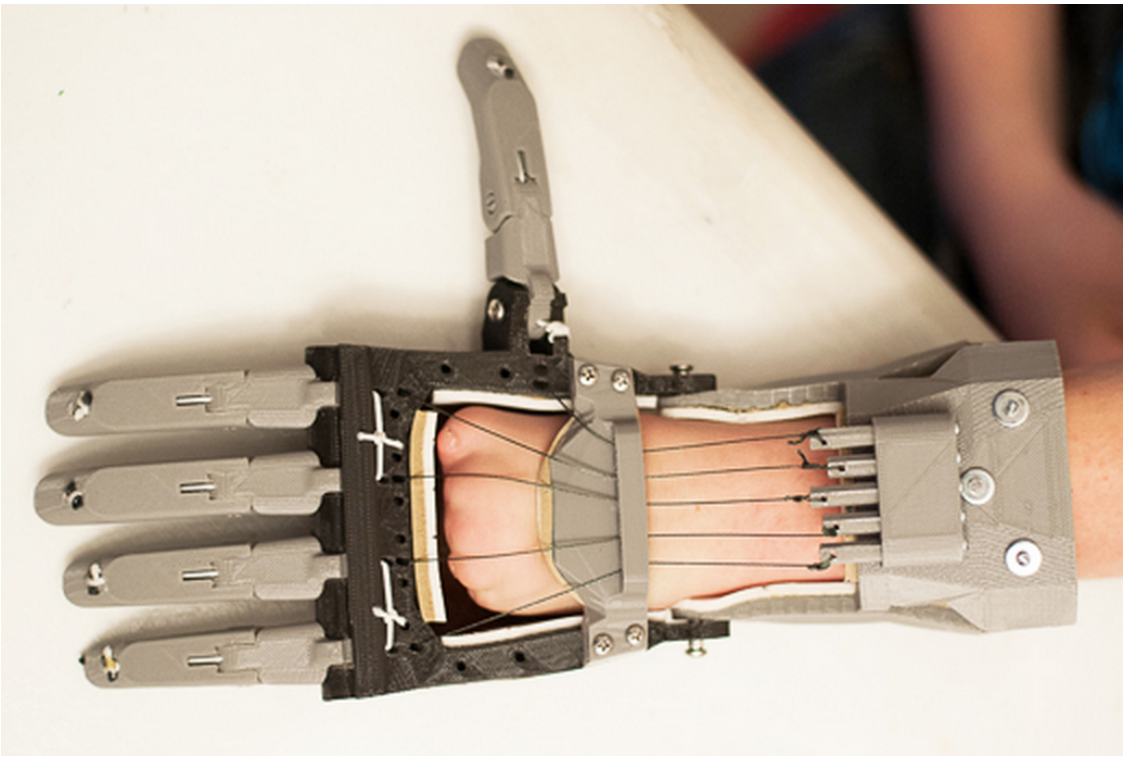
The Alternative Limb Project offers an extravagant, trailblazing look at the ability of design to redefine disability, but more accessible options are needed—ones that sit somewhere between invisibility and bling, the unaffordable and the unconvincingly basic.

Canadian company The Alleles offers a smart solution. Since 2012, they've been producing patterned covers in lightweight plastic, which can be strapped onto the titanium pole of below-knee prostheses. Retailing at around $400, they're a relatively affordable option that lets amputees introduce variety and personality into their prosthetic wear. Photographs on their website show models matching their prosthetics to their clothing, including Canadian para-snowboarder Michelle Salt rocking a coral-colored limb with a matching coral dress.

Emery Vandebaugh wearing an Alleles cover
Photo courtesy of Terry Oh

With the price of 3D-printers dropping and their technology improving, 3D-printed prosthetics might offer another solution. Designers can 3D-print limbs to order, instead of mass producing them and resizing them for individuals. Together with the inexpensive plastic filament these printers use, this brings the cost of a limb into the realm of the hundreds, instead of the thousands. The volunteer-based organization e-Nable is already using 3D printing to make functional prosthetic hands for kids and adults across the United States. Their chunky, colorful prosthetics resemble the gloved hands of superheroes and can be assembled in under a month for less than $50.



The Cyborg Beast hand
Photo courtesy of e-NABLE

Middle-of-the road prosthetics don't even have to be this high-tech. One cheap option involves decorating the socket of a prosthetic leg with laminated fabric. Sutton said she noticed a marked difference in the way people approached her as soon as she did this: "Color just changed everything." She told a story of a girl approaching her in a grocery store and standing before her in awe, unable to articulate that Sutton's socket matched her spotted dress.

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In a TED talk entitled “My 12 Pairs of Legs,” Paralympian, actor, and activist, Aimee Mullins, relays a speech she delivered to a group of 6-8 year-olds at a children’s museum. She asked the parents to let their children into the room on their own for a few minutes, so the adults wouldn’t brief or censor them. The children immediately descended on a table displaying Mullins’ legs—poking them, wiggling the toes, leaning their weight on the sprinting blade to see how it held.

“Kids,” Mullins said, “When I woke up this morning, I decided I wanted to be able to jump over a house— nothing big; two or three stories. If you could think of any animal, any superhero, any cartoon character, anything you can dream up right now, what kind of legs would you build me?”
“Kangaroo!” one child screamed.
“No, it should be a frog!”
“No! Go-Go Gadget!”
“The Incredibles!”
“Hey, uh,” piped up one eight-year-old, “wouldn’t you want to fly, too?”

Across my interviews, I found that it was often children who made and inspired bolder limb choices. An eight-year-old’s drawing of her dream leg encouraged de Oliveira Barata to start The Alternative Limb Project. A five-year-old’s decision to print Dora The Explorer on her leg pushed Priscilla Sutton to choose a patterned limb instead of a plain one. “Kids are naturally curious about what they don’t know,” Mullins explains. “They only learn to be frightened of those differences when an adult influences them to behave that way.”

Perhaps children — their excitement and their openness to ideas —can be taken as an indicator of how future generations will approach prosthetics, when the stigma that often surrounds amputation has dissolved, as it did for vision impairment. Perhaps people will begin to view prosthetics as a realm for creativity, for moving beyond the bounds of the body, for anything but invisibility.

Mullins concludes her talk: “And just like that, I went from being a woman that these kids would have been trained to see as disabled, to somebody that had potential that their bodies didn’t even have yet.”