

# An Intimate Laboratory? Prostheses as a Tool for Experimenting with Identity and Normalcy

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## ABSTRACT

This paper is about the aspects of ability, selfhood, and normalcy embodied in people's relationships with prostheses. Drawing on interviews with 14 individuals with upper-limb loss and diverse experiences with prostheses, we find people not only choose to use and not use prosthesis throughout their lives but also form close and complex relationships with them. The design of "assistive" technology often focuses on enhancing function; however, we found that prostheses played important roles in people's development of identity and sense of normalcy. Even when a prosthesis failed functionally, such as was the case with 3D-printed prostheses created by an on-line open-source maker community (e-NABLE), we found people still praised the design and initiative because of the positive impacts on popular culture, identity, and community building. This work surfaces crucial questions about the role of design interventions in identity production, the promise of maker communities for accelerating innovation, and a broader definition of "assistive" technology.

## Author Keywords

Prostheses; Ability; Assistive Technology; Identity; Normalcy; Design Interventions.

## ACM Classification Keywords

K.4.0 Computers in Society: general.

## INTRODUCTION

Over the last decade, the HCI community has built a rich body of work oriented toward "assistive" technology: the systems and infrastructures devised to help people with disabilities go about their daily lives. This work largely concentrates on building systems to enhance or replace human ability and complements investigations in the fields of prosthetics and occupational therapy. More recently, other work has recognized how the body and assistive technologies can become embedded in peoples' lives in

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Figure 1: Hand prostheses from 15th century to 21st century. Copyright: Peter Finer LTD.

ways that reach beyond function to consider affective and aesthetic identifications. This work has recently met up with discussions of customization, emerging in HCI studies of maker and hacker culture by examining the different definitions of "user" and "use" they present [7, 13, 17]. In doing so, HCI has continued to broaden its definitions of making and technology: asking who decides what something should do or look like across a broad range of projects, from online distribution platforms to small-scale manufacturing [10, 15, 32].

Our paper builds on this blending of maker sensibilities and assistive technology to consider the work of prostheses — the synthetic body parts such as legs, arms or hearts that augment the body — and associated grassroots fabrication communities, such as e-NABLE. In 2013, the e-NABLE community emerged from an online collaboration between Ivan Owen, a prop maker from the United States, and Richard Van As, a carpenter from South Africa. Together they created a 3D-printed prosthetic hand and Owen determined to release its designs freely online. Within a year, a community coalesced, building upon and improving the initial designs, making hundreds of hand designs available for public download [11].

e-NABLE organizers framed their initiative as the "3D Mechanical Hand Maker Movement," a loose network of artists, enthusiasts and engineers intervening in a medical establishment ripe for disruption. To many, it seemed the influence of 3D-printing, and what former *Wired* editor-in-chief Chris Anderson [4] has famously called a "maker revolution," would thoroughly transform prosthetic production. Specialized 3D-printers would develop

biomimetic tissues [18] and low-cost bots [25] would produce custom prostheses. Within the popular imagination of news media, this turn to open-source hardware engineering promised to upend a perpetual and tumultuous demand for medical resources and its sometimes-fatal consequences. But what has small-scale manufacturing and innovation actually brought to people's daily lives, and how might HCI help address these challenges? What, for that matter, might a study of everyday prostheses bring to HCI's examination of assistive technology?

This paper examines these questions by drawing on interviews with 14 individuals with upper-limb loss and our ongoing experiences developing and observing prostheses. Our research team was comprised of three design researchers and a mechanical engineer contributing to the design of assistive technology. Through our engagements and interviews we saw that while at first prostheses seem to invite an examination of functionality (extending what the body can do), upon closer inspection we find people also project ability-focused and normative identifications onto their prostheses (shaping what constitutes a body).

Three possibilities follow from this observation. First, we invite the consideration of "assistive technology" as not only tools for improving function, but also as important sites of identity production and experimentation. This possibility has important ramifications for HCI research as sites of technology development become increasingly entwined with the body, shifting who has responsibility for technical production, maintenance and development. Second, our work reminds HCI designers and scholars that ability and disability are not static categories. Instead, ability encompasses a complex array of social forces, including the economic constraints and institutional arrangements such as medical care.

Our final insight points to the important role communities like e-NABLE play in the development of ability identity, the sense of self produced through one's capacity to perform a given act. Shortcomings such as mechanical breakdowns, poor performance, and inconvenient maintenance threaten the physical support 3D-printed prostheses may provide. Yet e-NABLE demonstrates other provisions. More than support instrumental achievements, people use e-NABLE as a site of identity formation that helps people build new community partnerships and perceptions of self. This suggests that HCI analyses extend beyond individual users to consider the broader organizational structures at play: the way communities like e-NABLE may fall short in meeting certain expectations of the people they serve while supporting others.

Together, our examination of prostheses and e-NABLE allow us to rethink the "assistive" in the design of assistive technologies. What features we attribute as assistive, may in fact perturb certain actions while facilitating others. Here we challenge HCI research to account for these often hidden consequences of assistive technology development.

At stake is an attempt to define how people construct the self and ideas of normal in their own intimate laboratories.

## **DEVELOPMENTS IN PROSTHESIS DESIGN**

To understand the role of prostheses today and the promise they hold for HCI inquiry, we first review the current state of prosthesis design, fabrication, and use.

### **Prosthesis in Historical Perspective: Form and Function**

As an artificial device that replaces a missing or impaired part of the body, evidence of prostheses in daily life extend to the Egyptians [23]. Archaeologists have discovered a variety of prostheses with Egyptian mummies, including toes and hands with detailed paintings of features. The evolution of intricate devices to replace the hand (Figure 1) include the famous iron hand of Götzt von Berlichingen, an imperial knight and poet from the 15<sup>th</sup> century [42].

Since these early designs, people have developed numerous forms of prostheses to assist individuals with upper-limb loss. Prostheses can either be passive, worn for cosmetic reasons and having no moving parts, or active, enabling movement to enhance function. Active prostheses are typically body-powered, using a series of cables connected to other body parts, such as the shoulder, to create movement. More recently, companies have introduced myoelectric prostheses, [20] which use muscle activity to control movements of an electrically-powered device. To mimic the hand, various terminal devices are available for use at the end of the prosthesis. Prosthetists report that hooks are often considered functionally superior terminal devices because they allow people to see what they are manipulating and have high strength [5]. However, many people prefer terminal devices that look and feel like a human hand [6, 14]. The individuals interviewed in this study had diverse experiences with these many different types of upper-limb prostheses and, as we will see, had often tried one multiple designs.

### **Prosthesis Fabrication**

Prior to the late 1940s, prostheses were fabricated by generally trained 'fitters' [1]. Today, prosthetists receive graduate-level training and certification to fabricate, fit, and customize prostheses and sockets for individuals with limb loss [21]. During what can be a time-intensive process, they work with each user to determine the best prosthesis given their disability, personal goals, and medical coverage. In the US, upper-limb prostheses typically cost between \$3,000 - \$15,000, but sometimes upward of \$60,000 depending on the complexity and design.

Considering prostheses use, researchers have conducted several studies including [16, 31, 34], few of which are on people's perceptions of upper-limb prostheses beyond evaluating functional performance and acceptance. A literature review [19] described participants' adjustment and learning when transitioning to life with an amputation, finding supportive relationships crucial as they can encourage positive coping. Prostheses also contributed to allowing participants to feel whole again. Overwhelmingly,

this prior work has documented the experiences of people with limb loss through prosthesis usage and has targeted rehabilitation practitioners such as prosthetists and therapists.

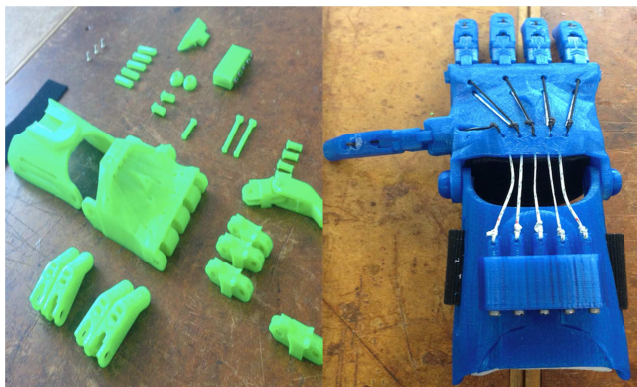
### **e-NABLE**

Since 2013, the e-NABLE community has contrasted with these traditional patterns of prosthetic fabrication to connect volunteers with people wishing to try 3D-printed hands (Figure 2). Though other organizations, such as the Open Hand Project [39] and Open Bionics [24], tout similar missions, we focus on e-NABLE here. e-NABLE focuses on underserved populations for whom traditional prostheses may be too expensive, such as for those without medical coverage, or impractical, such as for children who have limited options available and quickly outgrow their prostheses. Any individual who would like to receive a hand can submit an intake form on the e-NABLE website [11] and a volunteer “matchmaker” will find a local community member who can 3D-print a hand. Material costs for each hand are less than \$50 and are typically covered by the volunteers, outside donations, or the user. Volunteers and users often work together to customize the prosthetic hands to fit each person’s needs.

As of September 2015, e-NABLE has delivered an estimated 1,500 hands [11], but since designs are open-source and shared on Thingiverse [41], the entire impact is unknown. Few articles have been published about e-NABLE though Zuniga [46] compared the accuracy of measuring hands in person or based on photos to support the e-NABLE community. The rapid growth of the community and proliferation of designs in the past two years seems promising at the surface, although there are significant concerns from the medical community about the safety, reliability, and regulation of these hands [2, 22]. Here we explored the experiences of people who have used both traditional prostheses fabricated by certified prosthetists and 3D-printed prostheses from e-NABLE.

### **LITERATURE REVIEW**

In the sections that follow we consider two areas of the HCI and social science literature that inform our analysis: first,



**Figure 2: Pieces of e-NABLE hand (left) and assembled e-NABLE hand (right). Photos taken by research team.**

studies that examine how people associate meaning — and enact ideas of selfhood — with technical artifacts; and, second, work that investigates the production of prostheses and its recent attention in the maker movement.

### **Assistive Technology Objects and Identity**

To consider the production of identity around technology, the HCI community has readily turned to the symbolic interactionism of Erving Goffman and the psychology of Mihaly Csikszentmihalyi and Eugene Rochberg-Halton. These thinkers have led HCI researchers to the meanings people associate with technical artifacts through everyday actions, emphasizing the symbolism and affective identifications those artifacts enact for the individual and family [26, 27].

Other work breaks from a fixed notion of meaning to consider the production of meaning through performance — emphasizing the ongoing processual (rather than object-like) nature of values and identifications. A principle notion of selfhood in this area comes from feminist theorist Judith Butler, who emphasizes the continual production and reproduction of identity through daily encounters. “[T]here need not be a ‘doer behind the deed,’” Butler writes, “but that the ‘doer’ is variably constructed in and through the deed” [8]. Rather than endlessly fluid, the self gets maintained through its worldly engagements.

Taking these concerns to the practices of technology production in HCI, Suchman [38] and Van House [44] recommend treating a categorical distinction between human and machine as neither inevitable nor natural, but produced and enacted within a social and material setting. Building upon these thinkers, we consider the material setting for such technology production as it relates to designing for more types of bodies, and designing for the unique social settings with normative expectations that impact identity construction and production.

While largely absent in HCI literature, a rich discussion of assistive technology and identity production has emerged from the field of cinema and media studies. Considering the limits of age and ability perception, cultural theorist Kathleen Woodward [45] analyzes a 1975 image of a woman (artist Louise Bourgeois) walking the streets with a large latex costume designed to signal age. Making the point that our perceptions of ability raise cultural tensions, Woodward likens this image to an illustration depicting a pregnant older woman accompanied by a cane and other age-related objects. While technologies may change people’s abilities (here, older women), cultural imagery may remain fixed, refusing to rewrite its cultural scripts. These concerns for visibility and the body resurface in media theorist Vivian Sobchack’s [36] autobiography of living with a so-called ‘phantom limb’. Comparing her ability identity (what she calls “objective body”) with her affective identity (what she calls her “phenomenal body”), Sobchack reflects on her experience of losing her own lower limb to frame her condition as an “intimate

laboratory”: a site for examining, testing and reflecting on her body.

Our study builds on Woodward’s concern for the ability-marked body and Sobchack’s concept of the “intimate laboratory” to consider how assistive technology interfaces with the body as an experimental platform for identity production, specifically with a focus on individuals with upper-limb loss. While Sobchack’s laboratory remained tied to her “phantom” limb and body, the laboratory of our interviewees invites a range of design interventions. As we will see, this requires extending HCI’s treatment of the way things like prostheses develop capacities for identification and normative action.

### **Assistive Technology and Manufacturing**

A growing body of recent work considers the promise of collaborative tinkering around assistive technology through services like Thingiverse, a platform for documenting and sharing digital 3D-models [7]. In fact, researchers have recognized the potential for making to be an empowerment tool for people to create their own assistive technology [13]. Yet Buehler *et al* [7] found that makers and users of assistive technologies are largely disconnected. They recommend providing communication channels for easier collaboration among makers and users, more standardized search terms so assistive technology designs are easier to find, and more accessible tools as methods for closing this gap.

Regarding making and prostheses, Ratto’s [29] exploration of 3D-printing, prostheses, and their intersection helps distinguish computational processes meant for mass production from the art of making unique designs. They noted that all residual limbs differ and demand personalization. Other related maker communities include Schmidt *et al’s* [33] easy-to-use tool for scanning residual limbs and Record *et al’s* [30] open-source kit to educate communities about prosthetics and human augmentation. This work connects to Woodward’s concern for the cultural scripts that influence perceptions of ability and how individuals may use assistive technology to draft those scripts.

How maker communities and DIY will influence and shape cultural scripts related to assistive technology remains an open question. Advocates claim makers “are reshaping how people consume and interpret the handmade”. Informal learning websites such as Skillshare [35], help coordinate meetups and exchange techniques. Instructional how-to websites enable users to create and share online instructions for making, fixing and customizing everyday goods. Pattern-sharing websites such as Ponoko [28] complement co-working sites to offer a diverse means of sharing corporeal knowledge in person and online. In concert, researchers including a 2014 panel at CHI [3], Toombs *et al’s* work [43], and afore mentioned [10, 15, 32] question the espoused democracy of the maker movement where women and minorities are underrepresented. Toombs work

specifically deconstructs maker community practices to demonstrate the necessity of care and other collectivist values for community maintenance. Though we do not investigate democracy and representation here, the discussion is highly relevant as people with disabilities begin to be recognized as makers. Through examining how people make things and share them with others, scholars question how digital tools enhance people’s engagement and connection with the world. This paper examines the promise of maker communities and digital fabrication for assistive technology, specifically with a focus on prostheses.

By speaking with people about their lived experience with upper-limb loss, we ask two questions. First, *how do prostheses help shape the body’s role in ability and normative identifications?* To address this question we consider the ways participants presented themselves and how they incorporated prostheses and limb loss into everyday life. Second, *what emerges from maker communities who are aimed at “disruption” of century-old practices supporting people with limb loss?* We learn how the e-NABLE project works to support and sometimes disrupt its own beneficiaries, the people building and maintaining 3D-printed prosthetic hands.

Together these questions highlight how limb loss and prosthetic intervention interface to form an intimate laboratory through which people experiment with identity production, develop new concepts of normative action, and use making as a platform for communities coalescing to challenge notions of who should make and what should be made.

### **METHODS**

Our analysis draws on fourteen interviews with people with upper-limb loss and Steele’s ongoing work in prosthesis design. Nine adults were recruited through local prosthetists and five through an email to adults who received 3D-printed hands from the e-NABLE community. Given our questions about identity and normative discourse, we interviewed adults who have arguably had more experiences forming and presenting their identities, rather than children who have thus far constituted the primary group to which e-NABLE has distributed devices.

Our interviewees varied in their physical ability and use of prosthetic devices. In hopes of contextualizing our findings with characteristics of our participants related to limb loss, we recognize language commonly used in medical fields, and borrowed here, as ablest. Ten had congenital limb loss (born without part of their limb), and four had amputations later in life, most missing either parts of their hand or forearm (transhumeral / transradial). All had prior experience with prostheses to different degrees. While six participants used their prosthesis on a daily basis (myoelectric and body-powered), three others had extensive past experience using a body-powered prosthesis, but choose to not use their device anymore. The five people

who received e-NABLE hands chose to not use them, or any other prosthesis, regularly.

We sought stories during interviews by encouraging participants, anonymized with pseudonyms, to direct the conversation. We probed further by greeting responses with relevant follow-up questions. Prompts on the interview guide included ‘What does the term prosthesis mean to you?’ and ‘Tell us about a time someone noticed your prosthesis.’ Interviews were recorded and transcribed. We generated stories from interview transcripts based on successive rounds of open and thematic coding, alongside the production of analytic memos that we discussed among the project team as forms of intermediate writing (following Grounded Theory principles [9, 12, 37]). We used “vignettes” (short narrative reflections) to highlight the situated character of participants’ everyday engagements with prostheses, an approach applied widely in sociology and anthropology. The vignettes contextualize accompanying quotes that pinpoint how prostheses have influenced identity production and explorations of normalcy. In the section that follows we sketch some of these diverse and surprising encounters with prostheses in people’s daily lives.

## FINDINGS

Whether or not they “used” one, the adults we spoke with considered prostheses part of an ongoing process of development: of who they saw themselves as individually, of who they saw themselves becoming collectively, and of how they desired to look, act and relate to others across time. A first facet of this concerns their preferences for certain prosthetic interactions, conveyed through descriptions of their body and the formal qualities of their prostheses. Our interviewees further conceptualized normative expectations, sometimes complying with them to present a two-armed body while other times using limb loss and prostheses to violate those expectations. Cultivating attention from others, they described using interventions on their bodies as a basis for aesthetic exploration and embellishment such as costume. This interest in experimentation met its match in e-NABLE, a community that presented new technical opportunities. The people we spoke with dealt with functional failures such as faulty hardware and inaccessible assembly of their e-NABLE devices while recognizing the importance of the broader social network it supported, a community enriching opportunities to connect with other people with limb loss.

## Perceptions of Self and Ability

Across our interviews, we learned of experiences with prostheses that uniquely contributed to people’s formation and presentation of self. We found that a strong influent of identity production was in how they viewed themselves most able to function, sometimes with a prosthesis, and sometimes without. Although function guided whether they used a prosthesis, function was a fluid construct interpreted based on people’s ongoing sense of ability identity. We first highlight Christina, a prosthesis user whose prosthesis use became so deeply engrained that she felt switching devices threatened her sense of self. We continue by sharing stories from two participants who describe feeling most able when not using a prosthesis. With or without a prosthesis, presenting an able self became a focal point of identity construction.

### **From “The Girl with a Hook” to Having a Dazzling Arm**

We turn to Christina’s story which demonstrates how prosthesis use influenced identity through life transitions:

*Christina used prostheses all her life. At 17, she learned that insurance would change coverage when she became an adult. Her doctors encouraged her to try a more-expensive myoelectric hand, and the decision to transition did not come easily. She had built a strong identity as, in her words, “the girl with the hook.” She admitted that aesthetics was more important to her then, and the thought of fitting in as a girl with two hands at college sounded like a “real treat.” However, she struggled: “Learning to use the device was foreign to me.” Beyond the difficulty of learning how to function with the prosthesis, fitting in came with emotional costs: “My reflection in the mirror was no longer what I was used to. ...I felt like a sell out, I mean I felt ashamed of myself because I felt I valued cosmetics when I had done so much work on who I was.” Christina built an identity as a girl with a hook, but chose to try a new prosthesis to fit in at college as someone with two hands in an attempt to present a self that she perceived would be more normal to others.*

*Ultimately, she chose utility, switching back to using a hook instead of keeping the fancier hand, but she continued to use her prosthesis as a form of self-expression. “I decided that I was going to make a little bracelet of crystals for my forearm at the end, kind of like a tennis bracelet...So I had extra crystals (laughs) so I just kept going, and then I got more and more and more and it became a lot of fun, and it (Figure 3) gets a lot of attention and people love it. Like in the sun it is so sparkly, like carrying my own disco ball...It is my style, and it is a representation of me.”*



**Figure 3: Christina’s sparkly arm and Brian tying his shoe. Photos used with participant permission.**

*Christina explicitly used her prosthesis to present her identity. As a child, it defined her as she considered herself “the girl with the hook.” In hopes of better fitting in, she underwent the difficult identity and functional transition to a hand prosthesis. However, she ultimately decided that whatever cosmetic advantage a hand provided, she could present the most able self by switching back to a hook prosthesis. Now, she has decorated her prosthesis to represent herself and to guide the reactions from others. “When it had just been the black forearm, people used to look at it at the corner of their eye, but they would never start a conversation... [now] it gets a lot of attention and people love it.”*

*Not only does Christina’s sparkly prosthesis represent her, but she uses it to attract positive attention. Her very identity production has changed the way people around her view prostheses. What at first stifled conversation now accelerates it. Decorating an assistive device, which is assumed to increase function, deviates from others’ expectations and provides a platform for sharing.*

Christina’s story illustrates the malleability of self-presentation as mediated by limb loss, time, and circumstance. She was proud of the attention her prosthesis attracted and presented confidence in her daily life. Although she decided to try a more realistic prosthetic hand in college, as she matured, utility became the driving force when choosing a prosthesis. Yet aesthetics remained important to her, and she preferred to shape the attention paid her by making her prosthesis an eye-catching spectacle. Prostheses became a central part of her life, so integrated, that her notion of ability and her presentations of self could not be separated. What began as a mere device turned into a platform for self-expression, illustrated most clearly in her love for making jewelry. Christina’s body became an intimate laboratory of which her prosthesis was one component, providing physical functionality and a platform for identity production.

Christina’s story parallels the experiences of other participants who found prostheses an important part of self-presentation. Whether enabling activities from enjoying a

glass of wine in the evening to driving, prostheses often supported their desired presentation of an able and independent self. “*If I didn’t have prostheses, none of that would be possible,*” one woman explained. Recognizing that tasks could be accomplished “*independently*” with a prosthesis — whether pouring flour into cups without making a mess, or hammering nails while installing curtains — people often sought to prove others wrong about their ability, and this was reflected in how they presented themselves with prostheses.

***“The guy who is missing a hand, but can still do anything.”***

While prostheses played an important role in enabling perceptions of self for some individuals, we also found that identity and ability were tightly coupled for individuals who chose not to use a prosthesis. To understand this coupling, we turn to Brian, who described limb loss as “*being a big part of who I am.*” Brian heard the word “*disabled*” commonly associated with him, but didn’t identify with it:

*“Every time I call myself disabled, I mentally think that I am not actually disabled ‘cause I can pretty much do anything. But I just don’t really know a better term for it. Like I am the guy who is missing a hand, but can still do anything.”*

A congenital amputee, Brian tried prostheses as a child, but after he had “*already learned to do everything.*” He considered them “*unnecessary,*” noting they “*got in the way.*” He felt his prosthesis hindered his perception of his ability and developed several workarounds to complete tasks such as demonstrating to us how he ties his shoes during the interview (Figure 3). Today Brian considers himself a “*guy missing a hand,*” a description that demonstrates how tightly woven presenting an able self may become with identity production, so much so, that the ideas were even stated together.

Similar to Brian, Kelsey encountered prostheses as a child. Her limb difference is more pronounced, missing parts of both arms, but she also reported that she quickly learned she could complete tasks more quickly without a prosthesis. She humorously reflected that as a toddler, her parents enticed her to use a prosthesis to pick up M&M’s to eat: “*It was like I could eat 5 ... if I put my face down or I could put down my hand to pick up an M&M one by one.*” However, Kelsey maintains that although she does not use a prosthesis, she uses “*all*” things in her environment to complete everyday tasks such as using the hooked tines on a back scratcher to operate zippers, and secures utensils into foam tubes for easier gripping.

For both Brian and Kelsey, the utility of prostheses did not make sense at a young age, prompting them to denounce the devices on account that they were able to do anything without them. Rather, limb loss was deeply engrained into their bodies, an intimate site upon which they experimented by creatively interfacing with everyday objects to learn which repurposements worked best for them.

Although Brian and Kelsey had congenital limb loss, only ever knowing themselves and their bodies with a limb difference, we also found that those who had amputations later in life reported that prostheses could be a hindrance to presenting an able self. For example, Michael, whose arm was amputated after a motorcycle accident as an adult, found a hook prosthesis useless after attempting myriad tasks such as tying shoes or cooking: “[the prosthesis] is frustrating and not useful...after my accident, after trying it, I decided not to use it.” He further explained that he often dropped books as soon as he picked them up, finding that using a prosthesis “takes more energy than not using one.” Similar to Brian and Kelsey, Michael found creative ways to use objects from the environment: “in the kitchen, for instance, we have a pair of scissors ... I use that for soda bottles and things like that.” Similar to our prosthesis users, these individuals found clever modifications, including everyday objects, expanding their intimate laboratories and making their environments work for them.

The stories above show how people incorporated limb loss into their ability identity and how prosthesis could extend this identification to sites and systems beyond the body. Prostheses provided a helpful means of achieving tasks for some, but they also became platforms for experimenting with the body. All of our interviewees tried prostheses, as they navigated the interplay of ability and identity production in their daily lives. Christina communicated her enjoyment of fashion through her sparkly prosthetic extensions and Ben countered potential ableist assumptions by declaring he could “do anything” with one hand. Whether or not this prosthesis use continued, people tested and developed their ability identity through corporeal interventions.

### **Navigating Normalcy and Popular Culture**

As those we spoke with presented reflections of their perceptions of ability and self, tensions around ideas of normalcy emerged. Facing pressure to conform to the expectation that everyone should have a body with two hands, participants found ways to conceal limb loss. However, these efforts were often complex. They had to weigh other factors such as insurance coverage as they figured new ways to conform. Additionally, participants violated their perceptions of what society considers “normal” when they used their prostheses to gain positive attention and look “cool.” To understand this process we turn to the story of Elizabeth.

*Elizabeth grew up using prostheses. She described how consistent encouragement from her parents to wear her prosthesis had an impact on how she preferred to present herself as an adult. “I am actually not comfortable not wearing it in front of the people who I don’t know well. So my family and fiancé, that’s fine. Beyond that, I am a little uncomfortable. I think that’s because my parents emphasized it at a young age that I am supposed to wear it all the time. So I got used to that. And at this point, it has become my habit like if I don’t put on my clothes when I go*

*out. Even though sometimes functionally it might be better not to have it. That’s kinda like my thing that I am working on to get over.” Though Elizabeth suggested there may be benefits to becoming more comfortable removing her prosthesis in public, her habit of wearing it trumped practicality.*

*However, she also wore a prosthesis to present a two-handed body which she believed would defer unwanted attention. For example Elizabeth would deliberately ignore stares as she considered limb loss irrelevant to who she is. She prided herself in how long it took some friends to learn that she used a prosthesis. She humorously mimicked the surprise when describing her record time concealing her limb loss from friends: “I have friends who I know for 4-6 months. Sometimes people won’t notice until I start to wear short sleeves. And then they are like “wow”. That’s funny...I don’t really see a reason to bring it up because it doesn’t affect how I interact with people generally.”*

*Elizabeth even continued to wear her prosthesis while it was broken and she was waiting for a replacement. “For a period of about 6 months, my hand started to open very slowly. It got worse and worse, until finally it stopped working. I had to be careful to get it in the right and least inconvenient position (slightly open) for typing.” Her continued use of the prosthesis despite malfunction illustrates how important it was for her to present a two-handed self, and to even problem solve methods to continue using a malfunctioning prosthesis.*

*Though Elizabeth always wore her myoelectric hand in public, she was not always satisfied with its appearance. She used a rubber protective covering that not only prevented water from ruining the circuitry, but matched her skin tone. Elizabeth lamented that the coverings were expensive, and only covered by insurance every two years. However, they deteriorated much more quickly. Elizabeth had learned to draw humor out of her all-to-often discolored covering. She described that her current covering, which she had worn for a year and a half began to discolor after just six months. She laughed saying it is “ugly, but it’s doing pretty well.” It was clearly very important for Elizabeth to present herself with two hands, yet she had learned to cope with a discolored covering since cost prohibited her from purchasing them as often as she would like.*

Elizabeth’s story illustrates the complexities of a seemingly simple desire to direct attention away from her prosthesis. Her navigation of perceived societal expectations of a two-handed body demonstrates the tensions underlying the negotiation of appearing normal. Since Elizabeth had a life-long habit of wearing her prosthesis, she was comfortable wearing it. Further, she loathed unwanted attention toward her prosthesis and found that wearing it concealed her limb loss to the point that even friends did not realize it for a time. However, as outside circumstances such as her parents influenced her preference to wear her prosthesis

even when inefficient, outside circumstances led her to accept some annoying aspects of prostheses. Using humor to make fun of the poor quality coverings that discolor, she accepted that she must comply with her insurance company's purchasing schedule or pay financially and socially by having hands that appear differently. Though outside circumstances clearly played a role in negotiating normalcy, Elizabeth used her body as an intimate laboratory, experimenting with ways to conceal limb loss. By complying with perceived normative expectations, she uses the look of her body, such as her skin color and her biological hand, as foundations for how prostheses should work as forms of self-expression.

We found similar stories from our other interviewees about unique strategies for navigating normal. Sometimes, participants complied with assumptions that a body should have two hands. One woman described wearing her passive arm during adolescence to appear more normal, though the arm was actually purchased to assist with balance while swimming. The desire to present a two-handed norm extended out of the pool and into daily life. At other times, they drew positive attention to their limb loss and used humor as a platform for deviating from a two-handed norm. Christina, with her sparkling arm, deliberately violated perceived societal expectations to create her own normal. Others centralized their prostheses or limb loss into costumes, such as portraying a pirate or a surfer with a shark-bitten board: *"I dressed up as Bethanie Hamilton, the surfer girl, in high school for celebrity day. ... or a pirate for Halloween."* Multiple people elevated prostheses to spectacles at show-and-tell, yet chose not to use them in their daily lives. Each person found their own way to navigate normal, incorporating different influences and concerns, within and beyond their control into how they presented themselves to others.

### **The Role of the e-NABLE Community**

Next we consider how the e-NABLE community has leveraged an association between prostheses and Do-It-Yourself tinkering to steer attention toward limb loss and prostheses. e-NABLE has been successful in bringing prostheses to the forefront of the popular imagination by cultivating a community. In one example, the star of the movie *Iron Man* even volunteered to help design and deliver a custom hand for a 7-year-old boy [39]. However, the tools it provides are neither technically groundbreaking nor pragmatic. Ivan Owen described how the designs are *"nothing novel"* but based upon eighteenth century designs that were originally carved of wood. Rather, the novelty comes through the technology that enabled designers from around the world to connect and create together. Of our five participants who successfully received and tried e-NABLE hands, none used them for functional benefits. Instead, the e-NABLE hands offered people with limb loss (and some engineering or mechanical expertise) an opportunity to exercise more agency over their devices through co-creation. Participants perceived the connections the e-

NABLE community provided them as beneficial in other ways, as the next two stories of e-NABLE users illuminate.

*Donald spoke with us just one year after cutting his fingers off one hand off with a table saw. Though he recounted the experience while laughing, he detailed adjustments he has made such as asking his wife to open bottles and straining to fit his hand around his truck's door handle. He first investigated purchasing a passive prosthesis which would provide no function. He ranted about the quoted \$12,500 price tag, calculating during our interview how many months of social security he would have to allocate for the purchase. His pharmacist introduced him to the e-NABLE community, and he was paired with a volunteer who worked with him to redesign an open-source hand to fit his specifications. For example, since Donald had the palm of his hand, and original designs included a hand piece, the volunteer changed the design so a plate with a tension string could be stretched over his hand. However, similar to Kelsey and Brian's stories above, Donald found the prosthesis more of a hindrance than a help and resolved that when wearing it he "can't do anything." He described asking his wife for assistance assembling the hand, since it is "impossible to do one handed," and he has even tried to adapt the device to work better. He glued an arthritis glove over the hand in hopes of gripping objects more easily, but he has yet to find a glue that adheres to the hand for more than one day. Despite these functional failures, the hand gave Donald an opportunity to connect with others grappling with these design challenges. He revered the e-NABLE community for their intent, reiterating that, "It's all volunteer. There's no cost to me, not even shipping."*

The above story begins to show how e-NABLE impacted our participants, but not in the way one might expect. For those with shop experience such as Donald, e-NABLE provided an opportunity to improve the design of prosthetic hands by collaborating with like-minded makers. Though the e-NABLE device failed functionally, the volunteer effort the operation afforded offered an appealing alternative to more expensive devices: *"This whole e-NABLE organization that's reaching out to thousands of people all over the world to be able to help. I think that's just tremendous."*

Next we consider how another person we spoke with chose not to use their e-NABLE hand, but similarly found the mission venerable, and the community supportive.

*James was born with no fingers on his right hand. When James traveled to his first e-NABLE convention he was walking with his left hand in his pocket and demonstrating what he called "reclusive" social conduct. At the event he met a one-handed chef. The chef's achievements challenged James's ideas of his own ability. James explained: "He's able to do his work as well as anybody else."*

*Since the convention, James has come out of his shell to detail stories of his contribution to assistive technology.*



*James volunteers as an accessibility instructor, using his limb loss to support prosthetics education and is comfortable sharing his limb loss with others. Like Donald, he described that the device did not improve his function – “I really can’t use the hand” – and that the hands had failed multiple times; however, he excitedly detailed each design he had received. He was clearly engaged with the process, stating that “I’m so fascinated by this [the e-NABLE community] ... I really have lived my life with this thing and I see a lot of hope for the future for people who are born with limb deficiencies.” Donald, even posited that: “I’ve been thinking of getting a 3D-printer myself.”*

Like Donald, James did not gain function by using an e-NABLE hand. However, they both learned something from the community made available to them by e-NABLE. Through meeting others with limb loss and working collaboratively on designs, they began to project new meanings onto ability. For Donald, the community offered opportunities to connect with others to improve upon the design of his hand. For James, meeting others with limb loss helped him to become more comfortable with his own body and to share limb loss with others to promote further low-cost and innovative prosthesis design.

Participants also expressed how the e-NABLE community has brought images of limb loss to popular media, providing a platform for transforming their own and others’ perceptions of normalcy. As one e-NABLE recipient shared: *“One of the fantastic things is [e-NABLE] raises awareness and it makes AT [assistive technology] cool and brings it to popular culture ...in the public attention ...all of this positive attention instead of negative attention.”* Some explained that the e-NABLE community offers a platform for flexibility, by designing and creating hands that can be personalized and created to emulate spectacles in popular culture. For example, Steve, who was born with no fingers on his left hand, co-created an e-NABLE hand out of curiosity, explaining: *“[its] rather big and super hero looking,”* but *“as of now, I have not found a use for it.”* Steve regularly shows his e-NABLE “super hero Avenger’s” hand to children, rarely using it otherwise.

Making prostheses “cool,” in Steve’s words, and playing on what uses of prostheses elicit attention, connected with people’s interest in other forms of creative repurposing. Decorating, augmenting, and customizing prosthesis and other assistive technology were important aspects of prostheses engagement for our interviewees. Adornment could take the form of temporary adjustments, such as incorporating prostheses into Halloween costumes. After dressing up as a pirate, one woman continued to share how her friends without limb loss wanted their own prosthesis. In response, they stretched out wire hangers, pushed the elongated wire up their sleeves and curled their fingers to reveal the hook-like top of the hanger. In other moments, prosthetic interventions became more permanent, such as Christina’s sparkly arm.

Here, we saw participants acting in anticipation of and in response to an imaginative engagement with their prostheses, often garnering positive attention socially. Indeed, participants imagined new uses for prostheses before and without e-NABLE. In this sense, rather than transform the field of engagement, e-NABLE begins to extend the range of possibilities for people with limb loss to present themselves with a variety of prosthetic forms.

## **DISCUSSION**

Our study has begun to draw out the vastly different roles prostheses can play in the production of ability identity and the navigation of normalcy. We observed participants’ desire to present capable selves, whether they use traditional prostheses, 3D-printed prostheses or none at all. Some deferred attention — Elizabeth’s efforts to ignore “stares” unless confronted directly — while others took advantage of opportunities to gain positive attention from their peers about their prostheses, from incorporating limb loss into costumes to Steve’s “Avenger’s” e-NABLE hand.

In parallel, the e-NABLE community illustrated paradoxical benefits when compared to the design of assistive technologies that often prioritize function. While the e-NABLE community may inspire people with limb loss to co-create and come together for a common cause, the hands thus far present serious challenges to engagement. Recall Donald’s attempts to make his hand more useful and James’s lack of confidence, which shifted with the emergence of new connections with others, working and making through limb loss. e-NABLE thus extended the range of possibilities already at play in our interviewees’ social worlds.

But what does this work have to do with assistive technology or maker developments in HCI? And how might HCI learn from these findings? As the HCI community continues to expand its interest in the largely separate spheres of accessibility and making [7,13], our findings illustrate how these communities may blend in ways that shift the stakes of assistive technology, and redefine the relationship between ability and the body. For our interviewees, we see both mundane modifications and e-NABLE narratives surface new tensions around the ability-marked-body. They begin to trouble an often-assumed binary of ability and disability that inform broader cultural expectations. The fact that technology can be used to extend capacities to engage in private and public life, suggests HCI scholars might forge new partnerships with existing community stakeholders to accommodate these possibilities, identifying new social mechanisms that use assistive technology design to promote and celebrate myriad abilities from the ground up.

Treating such tools as social mechanisms suggests viewing assistive technology as an important site of material and symbolic experimentation. This extends Sobchack’s idea of the “intimate laboratory” to emphasize the range of interventions that refigure the body. Prostheses not only

help people with instrumental actions (pick up food or drive), but also produce shifting identifications and conceptions of normalcy. Dressing up as pirates or a surfer with one arm, participants positioned their bodies as material sites of creativity and experimentation, impersonating others with limb loss to construct different types of bodies and associated ability identities. By considering assistive technology — and e-NABLE in particular — as an integral dimension of this experimentation, we begin to surface alternative concepts of what a body is, and to recognize that assistive technologies, as other objects, can play crucial roles in identity production. It is by recognizing the consequences of experimentation that we may weigh and prevent pitfalls as this work continues.

As it stands, the development of assistive technology and prostheses is laden with unspoken goals of replacing or augmenting human ability in an effort to move people with limb loss toward particular forms of normative action. Understanding assistive technology as affording such inclusion proffers an incomplete narrative wherein technology development remains the primary site of experimentation. Instead, we consider what fixtures design may influence to allow the body to interface with objects, to constitute new assistive configurations, and to negotiate sites of self-expression. As alluded to above, the importance of imagination in this experimentation remained central — as it prompted participants to leverage objects in their everyday environments to create clever and practical assistance unintended at inception (e.g., Kelsey’s utensils secured in foam tubing for easier gripping). Broadening the definition of assistive technology not only invites us to reimagine how we refer to devices but it opens the door for the HCI community to consider the importance of extending the indeterminacy of prosthetic encounters beyond function. Such extensions should incorporate the narrative of the unique but underrepresented discovery that comes with the experience of limb loss that shaped our interlocutors’ lives.

As HCI continues to examine the intersections of maker culture and assistive technology, we confront new questions and challenges. Assistive technology, as explored through experimentation with the body, now invites a consideration of what exactly the “assistive” is all about. Does assistive technology allow people with limb loss to reimagine how their body can define normative action, or does it extend lines of imagination already in place? Does it help us develop our notions of how one body can “exceed” another or rather how a body can be done differently? A bottom up approach of providing materials to make the body whole again connotes a stopping point. However, experimentation defines no whole, no stopping point at which any body is “normal.” It is here that we challenge communities of makers such as e-NABLE to begin to subtly build on people’s ongoing processes of experimentation. Rather than

start a revolution, new efforts of small-scale manufacturing may enliven existing facets of sociotechnical life.

## CONCLUSION

The stories above have described experiences of people with limb loss who confronted prescribed and 3D-printed prostheses. We learned that presenting able selves was incredibly important to our interlocutors, as they used a variety of tools and language to perpetuate a particular ability identity. We also observed deeply-held perceptions of what is normal. Sometimes compliant and other times defiant, people incorporated multiple ideas of self-presentation into their own definitions of normalcy. Though new, the e-NABLE community has already begun to elicit similar features of identity production. The benefits that we observed — connecting makers and people with limb loss, allowing people with limb loss to become more comfortable with their sense of self, escalating prostheses into popular culture — reflect roles of assistive technology often overlooked based on definitions that prioritize function. Our work helped surface crucial questions about the role of design interventions in identity production, new directions for the maker community as it intersects with assistive technology, and, ultimately, challenges to current definitions of “assistive” technology which prioritize function and often neglect the intimate laboratories they inhabit.

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