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e-NABLE: DIY-AT Production in a Multi-Stakeholder System

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by

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Abstract

The e-NABLE community is a distributed collaborative volunteer effort to make upper-limb assistive technology devices available to end users. e-NABLE represents a do-it-yourself (DIY) approach to traditional prosthetic care. In order to learn about the attitudes and challenges of stakeholders working in and around e-NABLE, we conducted interviews with 12 volunteers in the e-NABLE movement and 3 clinicians. We found that volunteers derive a rich set of benefits from this form of altruistic activity; that both volunteers and clinicians recognize that end users benefit from aesthetic customization and personal choice in device selection; and that volunteers and clinicians bring separate, but potentially complementary, skills to bear on the processes of device provision. Based on these findings, we outline potential ways for volunteers and clinicians to optimize their talents and knowledge around the end goal of increased positive patient outcomes.

Keywords: Accessibility; Assistive Technology; DIY; Limb Difference; Prosthetics; 3D Printing; Digital Fabrication; Making

e-NABLE: DIY-AT Production in a Multi-Stakeholder System

"We're in a cosmic sweet spot: right time, right place, smiling children, weeping parents, rejoicing nerds." —Participant V03

Traditional prosthetic devices are expensive—not only because each one is highly customized to a specific user's body, but because the cost of acquiring a device includes the services of a trained professional; from counseling, to trying out devices, to fitting, to follow-up and aftercare. Because devices are costly, and because children grow out of them quickly, inexpensive home-fabricated prosthetics can appear to be an attractive option to the family of a child with a limb difference. However, most families do not have access to home fabrication technologies, such as 3D printers, nor the specialized skills needed to design customized objects.

In 2013, e-NABLE emerged as an online network of individuals who design, fabricate and deliver upper-limb prosthetics to people who request them, free of charge. e-NABLE is a loosely knit global movement of volunteers. It comprises, among others, assistive technology (AT) designers, fabricators, and recipients. e-NABLE represents a coordinated, decentralized initiative to deliver the means of producing 3D-printed upper limb assistive technology to any user or any advocate for an end user.

Rationale

Several aspects of this community make it worthy of study in human-computer interaction. This community represents distributed digital design and fabrication. e-NABLE develops semi-standardized designs that, in each case, must be highly customized to an end user. Variations in limb size, limb length, and the presence or absence of fingers mean that producing a device for an end user is akin to tailoring a garment. This activity often occurs at a distance, i.e. when the fabricator and the recipient are not in the same location. The factor of distance presents challenges to the process of device provision. Explicating sociotechnical aspects of this community can inform future efforts that involve personalized fabrication at a distance.

Although some have observed a measure of hype around the so-called "maker movement" (Bean & Rosner, 2014; Jenkins & Bogost, 2015), it is precisely the small-scale, personal nature of "making" that marks it as a tenable production mode for certain custom applications, such as prosthetics. Initially, home fabrication may be indistinguishable from sloppy tinkering. Over iterative refinement, though, improvements on prototypes can converge on a design for a product that has been carefully tailored to a small niche of end users — or indeed, to a single user. Part of this is made possible by the ethics of open knowledge exhibited by communities of makers, similar to the practice of building upon the work of others that is found in Free and Open Source (FOSS) software development communities.

Custom-fit upper-limb prosthetics as produced by e-NABLE are one example of such a bespoke fabrication project. Assistive technology fabricated by amateurs is known as Do-It-Yourself Assistive Technology, or DIY-AT (Hurst & Tobias, 2011). The design and production of DIY-AT for others by a distributed confederation of collaborators is the focus of the qualitative study described in this report.

We posit that individuals who want to 3D print assistive technology for others at a distance encounter both obstacles and satisfaction throughout the process toward a finished product. Further, we are interested in the perspectives of clinical professionals who work in the prosthetics/assistive technology industry. We seek to understand the nature of e-NABLE volunteers' experience by asking questions including: What drew them to volunteer this way? What sorts of challenges or dilemmas do they encounter? How do they navigate these obstacles, and persist through the task of fabricating an assistive device? We seek to understand the reasons that clinicians' knowledge and skills are not more prominent in amateur AT fabrication communities, and what may be gained if their presence were to be more prominent. By studying these factors, we hope to gain insight into the experience of e-NABLE volunteers, and by extension, to gain deeper understanding of the phenomenon of DIY-AT for others at a distance.

Because of the wide-ranging and open-ended nature of e-NABLE, and in order to allow research directions to emerge from empirical observations, we selected interpretive grounded theory as the methodology to apply to this study. The word theory, in the context of grounded theory, refers to a set of ideas that is intended to explain facts or events.

Guided by constructivist grounded theory (Charmaz, 2014), we applied interpretive qualitative methods to analyze the e-NABLE community and its activities. Grounded theory is part of a class of qualitative research methods termed "emergent," or inductive, indeterminate, and open-ended. Emergent methods, as described by Hesse-Biber & Leavy (2010, p. 5), are "useful for discovering knowledge that is … difficult to tap into, because it has not been part of the dominant culture or discourse."

Charmaz (2014, p. 115) positions emergent methods as follows: "Emergent methods are particularly well suited for studying uncharted, contingent, or dynamic phenomena. These methods also allow for new properties of the studied phenomenon to appear that, in turn, shape new conditions and consequences to be studied. By adopting emergent methods, researchers can account for processes discovered in the empirical world and direct their methodological strategies accordingly."

Scope of the Study

We set out to study the experiences and values of a wide array of self-identified e-NABLE members. A given participant's ability to fabricate assistive technology was not a requirement for inclusion in the study. We limited the scope of this study to the values, attitudes and challenges of adult (over age 18) volunteers with e-NABLE, as well as clinicians who are either directly involved with e-NABLE or otherwise familiar with the group. We used an online screening questionnaire to identify an initial batch of participants. We discarded one response from an individual under age 18.

Definition of Terms

The terminology used in this report is consistent with the conventions of the e-NABLE community: the term *limb difference* denotes any reduction in the size of a limb, whether from birth, as a result of trauma, or medical amputation. We use the term *device* or *assistive device,* rather than "prosthetic," to refer to the products of the fabrication activities. In medical literature, *cosmesis* refers to a device's quality of mimicking an unaffected limb. We expand the term *cosmesis* to include a device's quality of managing visible stigma—that is, a strategy for attaining social acceptance (Goffman, 1963)—regardless of whether the device in question resembles a natural form.

We also note that the term "reflexive" has different usages across two different contexts in this report. The qualitative methodology used in this study demands "reflexivity" from the researcher/interpreter, which refers to a researcher's responsibility to pay careful attention to their own role in the construction of knowledge throughout the study. The report also refers to “reflexive volunteering,” a form of contribution that has benefits for the volunteer, not only for those served.

Literature Review

We present an overview of related literature along five major themes. The first involves the "maker movement," a recently-named phenomenon that involves fabrication in the home, often by amateurs. The second area we review, do-it-yourself assistive technology (DIY-AT), is a specific type of making that involves creating technology to facilitate daily life for end users with special needs. Third, we review historical instances of volunteer fabrication of valuable goods. Fourth, we review literature on motivations for volunteering. Finally, we review the background of clinical care for upper limb difference, including professional prosthetics provision.

The Maker Movement

Recent studies of maker and hacker culture assert that small-scale fabrication ("making") intersects with the tangible, physical and material aspects of HCI. Lindtner, Hertz & Dourish (2014) observed that maker practices represent an emerging form of prototyping products. Tanenbaum & Tanenbaum (2015, p. 2603) assert that making is more than a collective and creative hobbyist practice; rather, that home fabrication represents democratized access to technological practices that allow participants to express "playfulness, utility, and expressiveness." Bennett, Cen, Steele & Rosner (2016, p. 1745) observe that discussions of customization in HCI expand the number of potential definitions of "user" and "use," democratizing access to the ability to "decide what something should do or look like." e-NABLE represents an online community of makers that is experimenting in just this way, blending utility and expression in the instantiation of physical objects that are designed with computer-assisted methods.

Do-It-Yourself Assistive Technology

Traditional assistive technology (AT) may be unsatisfying because it is generic, impersonal, or too expensive to acquire. Do It Yourself Assistive Technology (DIY-AT) came about as a means to address the unsatisfactory aspects of clinically-approved assistive devices. DIY-AT producers aim to provision customized assistive technology for individual users, often at reduced cost (Hurst & Tobias, 2011).

Custom-made assistive technology is compelling for a number of reasons identified by Hook, Verbaan, Durrant, Olivier, & Wright (2014). Even individuals with the same general category of affected limb can have very different personal geometries. The topography of the residual limb, the muscle strength, and the activities of daily living all have an impact of which assistive technology can be used by a person. Also, an individual's personal context, including culture, life circumstances, and personal opinions can result in wide variation in how they chosoe to use AT in any given case. De Couvreur & Goossens (2011, p. 5) reinforce this framing of disability as “a complex interaction between features of a person's body and the features of the environment and society in which he or she lives.”

In the context of upper-limb prosthetic devices, the opportunity to obtain free devices for children can be especially compelling for parents and caretakers, for a variety of reasons. Krebs, Edelstein & Thornby (1991) reported that the use of an AT device by a growing child can support muscular development and gross motor skills. Krebs, Edelstein & Thornby (1991) also noted that children grow faster than the rate at which a family can acquire traditional devices at an affordable cost. Obtaining prosthetic devices through traditional channels, whether medical or governmental, can come at a high cost, take a long time, and ultimately deliver an unsatisfying device (Copley & Ziviani, 2004; Cowan & Turner-Smith, 1999). By contrast, the ability to customize digitally fabricated AT can allow a user to select a personalized device that aligns with their present needs, whether functional, cosmetic, or a blend of both. e-NABLE provides a method for end users to request personal devices, at least, with some evidence of personalization and customization described in the sections to follow.

Rapid production of digitally-fabricated assistive technology allows a user to receive a succession of multiple devices to be provided as their limb, social environment, and particular needs change. Digital fabrication methods also allow task-specific devices to be produced, and interchangeably worn as needs arise (Hofmann, Harris, Hudson, & Mankoff, 2016).

Hook et al. (2014) interviewed parents and caretakers of AT users to uncover their attitudes and barriers to DIY-AT fabrication. They listed several factors that bear on caretakers' self-perceived ability to produce assistive technologies: technical obstacles, attitudes toward the risk of investing time without producing results, issues around device aesthetics, and concerns about durability and safety. However, the findings in Hook et al. (2014) were related to AT that was designed and implemented on a small scale, in isolation. e-NABLE's blend of distributed development with individualized customization and production lessens the effects some of the listed factors. By distributing the work of device provisioning across design, fabrication and recipient advocacy roles, e-NABLE allows participants to access subsets of the qualities identified by Hook et al. (2014): recipients have a smaller obligation of time, fabricators bear the burden for construction, and designers concentrate of building in function, durability, and safety.

Hook et al. (2014) recommended that stakeholders explore rapid prototyping and “development of practical services and communities that support and encourage larger numbers of non-professionals to become involved in making and adapting AT” (p. 598). e-NABLE represents an early form of such a community.

Several recent studies have examined personal fabrication of DIY-AT. Hurst & Tobias (2011) identified motivations for end users to fabricate DIY-AT; these included personal passion, cost, and the ability to customize designs.

Buehler, Kane & Hurst (2014) studied 3D printing related to students with special support needs. They found that developing skills for 3D design and fabrication encourages learning in STEM (science, technology, engineering and mathematics), and that 3D printing can be used to create custom adaptive devices.

In a separate study, Buehler et al. (2015) examined the potential impact of Thingiverse, a 3D object repository, on DIY-AT practice. They found that many of the AT designers on Thingiverse “have no formal training or expertise in the creation of assistive technology” (p. 525). This seems to be borne out in the composition of e-NABLE's makers.

Moraiti, Venden Abeele, Vanroye & Geurts (2015) evaluated a toolkit to assist occupational therapists in making DIY assistive adaptations to soft objects. From their evaluation, they derived five guidelines for creators of toolkits for DIY-AT:

1. A DIY-AT toolkit should ensure that it can deliver a diversity of solutions to tailor a diversity of clients.
2. DIY-AT toolkits should support creativity, and allow for hacking and repurposing everyday objects.
3. Any toolkit should aim to provide therapists with the confidence that building these solutions is easy.
4. Toolkits should include means to offer meaningful feedback about the AT from end users to therapists.
5. Toolkits should provide an online support platform.

e-NABLE does not align strongly to many of the guidelines put forward by Moraiti et al. (2015). The guidelines presuppose a therapist in the delivery of care, which is not always clearly the case in e-NABLE. As regards a diversity of solutions, e-NABLE's main offerings are limited to a few designs for grasping assist devices. As regards hacking and repurposing everyday objects, the main e-NABLE designs require a 3D printer to generate much of the AT device. As regards meaningful feedback from end users, there is little apparent evidence of feedback channels. There is, at least, an online support platform in the form of e-NABLE's online forums.

Hurst & Kane (2013, p. 636) also noted the importance of online support platforms like e-NABLE in helping a wider range of individuals produce assistive technology: "Online communities can provide individuals with valuable knowledge of existing technology solutions that can help them make informed decisions about whether or not to adopt a new technology. Additionally, the ability to rapidly prototype and customize technology can also help them make the decision to adopt or modify existing technology (as needs or preferences change)."

In the specific domain of upper-limb DIY-AT, Zuniga et al. (2015) have designed an open hardware 3D printed body-powered upper limb prosthetic. For a period of time, it was used in the e-NABLE community. It is called Cyborg Beast and was designed in partnership with e-NABLE members. Its design priorities included ease of assembly and aesthetic appeal.

Volunteer Fabrication over Time

Volunteer fabrication projects have a long history. One example is during wartime, where on the so-called "home front" volunteers produced care packages for soldiers, wrote letters of support, knit socks, and cooked food (Head, 2009). In the 1940s, the Red Cross Production Corps coordinated 3.5 million volunteers in the production of sewn, knit and other soft goods for servicemen and clothing for refugees (Christiansen, 2011). Today, international organizations like Engineers Without Borders and Habitat for Humanity focus on reducing suffering through volunteer fabrication efforts.

Online distributed development communities may be regarded as cases of virtual volunteering, “in which volunteers conduct their activities for agencies and clients over the Internet, in whole or in part” (Cravens, 2000, p. 120). Free and open source software (FOSS) development is characterized as a form of virtual volunteering (Davidson, Mannan, Naik, & Dua, 2014). The e-NABLE community shares some characteristics with FOSS production and virtual volunteering. We posit that the motivations of volunteers joining the project and the structure of the volunteer work that takes place may be informed by the lens of FOSS development.

Volunteer Motivations

Because e-NABLE, as an open hardware effort, is similar in some ways to distributed free and open-source software (FOSS) development, it is instructive to note the existing literature around FOSS volunteer motivations.

With regard to volunteering in general, taking a wider view than FOSS, the motivations of volunteers are a well-studied phenomenon. Hustinx & Lammertyn (2003) identified two factors: a sense of community duty bound up with a desire for a sense of belonging—the *collective* style of volunteering—as well as a desire for self-realization and the fulfillment of personal goals—the *reflexive* style. Hustinx & Lammertyn (2003) do not see these styles as incompatible or exclusive. Rather, each volunteer experiences both styles as a blend on a personal spectrum.

Shah (2006) identified two types of FOSS developer, both of which work in a self-benefiting reflexive style: the *need-driven* developer and the *hobbyist*. The need-driven developer starts as a user, encounters a need for some personally-desired functionality, and becomes a developer in order to fill the gap. Shah notes that most FOSS developers fall into the *need-driven* category. The hobbyist participates for other reasons such as the joy of solving a puzzle, personal development, or the feeling of making a positive contribution.

Many of the e-NABLE volunteers we interviewed do not have a limb difference, nor are making devices for family members, so they are not able to be need-driven. Viewed through the lens of FOSS volunteering, they are hobbyists.

Upper Limb Difference, Clinical Care and Prosthetics

Incidence of Upper Limb Difference.

The Centers for Disease Control estimates that about 0.70 out of 2,000 children, or 1,454 children per year, are born with upper limb reductions in the United States (Parker, et al., 2010). In an 11-year total population study of the Stockholm, Sweden region, Ekblom, Laurell, & Arner (2010) found the incidence of congenital anomalies of the upper limb (not only reductions) to be 4.3 cases per 2,000 live births. Based on the subcategories reported by Ekblom, Laurell, & Arner (2010), the incidence of congenital limb reductions in the Stockholm study was 0.99 in 2,000.

Matching People and Technology.

Selecting an assistive device can be more complex than choosing one from a catalog based on aesthetic appearance. In the context of clinical care, Murray, Kelley-Soderholm, & Murray Jr. (2007, p. 288) note that there are many considerations to make when matching an end user to assistive technology: “Practitioners should assess the child's academic, social, and emotional functioning in addition to assessments of physical functioning. The findings of this study suggest that assessment of the families of children with upper limb differences should include their immediate and extended family relationships, the well-being of the children's siblings, the social support the family receives from friends and organizational affiliations, their financial resources, and the extent to which family members are knowledgeable about upper limb differences and their medical treatment."

This implies that an informed match between an individual and a device involves more than issuing a patient with a prosthetic that fits the body. The entire social context around the user should be taken into consideration. These holistic principles of care are echoed by the values of the Adaptive Design Foundation (Adaptations, 2015) in their Six Principles of Fabrication: "Before a device is used, the team must agree that the adaptation is: 1. safe, 2. needed, 3. wanted by the user and the team, 4. attractive, 5. durable, 6. made with materials that are eco-responsible, locally available, and at low or no cost."

Device Abandonment.

It is not unusual for an upper-limb AT device recipient to stop using that device entirely, known in the prosthetic literature as "abandonment." In a survey of literature about prosthetic abandonment, Biddiss & Chau (2007) noted that device "abandonment" is not unusual. Single-handed users may carry on with life without using a device at all. Biddiss & Chau report that 90% of activities of daily living can be accomplished with one hand, and that up to 89% of individuals felt less encumbered when they did not wear a prosthesis. Biddiss & Chau (2007) reported that the rate of device rejection ranged from 16% to 66%. The rejection rates among children were higher than those of adults. Body-powered devices in particular have the highest rates of abandonment. Factors behind this rate of rejection included awkward, slow movements, relatively weak strength of grip, and the high energy expenditure needed to operate them. It would seem counterintuitive, based on these findings, that the e-NABLE devices would be satisfying for end users.

In a survey of 227 adults who use traditional AT, Phillips & Zhao (1993) found that 29.3% of AT devices are completely abandoned by their users. They identified four predictive factors for device abandonment: lack of consideration for user opinion, poor device performance, changes in user needs or priorities over time, and ease of device procurement. Paradoxically, they noted that increased ease of acquisition of a device correlates with a higher chance of the device being abandoned. At the time of their study, the type of devices that were easiest to acquire were mass-produced, off-the-shelf, inexpensive appliances. They were unsatisfying because they were generic. e-NABLE devices are, by contrast, highly customized devices. Ease of acquisition need not be a negative factor if it is counterbalanced by personalization. It is possible that the high degree of aesthetic customization is a significant factor in e-NABLE device adoption.

Psychosocial Support for Device Users.

Rumsey & Harcourt (2007) found that for children who have a limb difference, social interaction is the locus of many of the most frequent difficulties related to the difference. Children construct their body image based on reactions from others in their social setting. A positive perception of self is informed to a great extent by peer perception. In one study (de Jong, et al., 2012), children shared that negative social interactions such as teasing, staring, and rejection played into negative feelings about their affected limb. Other participants in the study related that being treated with respect and admiration by peers allowed them to feel personal acceptance and even pride in their limb difference. In an HCI study, Shinohara & Wobbrock (2011) found that certain AT can mark users as “disabled,” and called for devices to be designed for social acceptability (minimizing stigma). Seen through this frame, the robot-like e-NABLE devices can represent a paradox. They make the user stand out, calling attention to their limb difference. The significant factor at play may be end user agency. Unlike a mass-fabricated prosthetic device, e-NABLE devices stand out in ways the user has specified and chosen for themselves.

Summary

After review of relevant literature, we learned that amateur fabrication has emerged as a rich area of study in the HCI research community. DIY-AT has emerged as a specific topic within studies of makers. Parents and caregivers are unlikely to carry out DIY fabrication of AT; volunteer makers have stepped into that gap in the form of e-NABLE. Upper-limb prosthetic devices are the most prevalent form of e-NABLE's work. Volunteer makers are likely to be motivated both by the altruistic nature of the activity and by the ways they benefit from working in their chosen application space. We learned that clinical professions have studied the factors that lead end users to abandon assistive technology; briefly, lack of personalization and inability to confer benefits that outweigh the negative aspects of living with a device.

This review provided background on the state of prosthetic care and DIY-AT, but we did not find research related strongly to situations where amateur volunteers carry out prosthetic device provision, work that is traditionally performed by professionals. This study is motivated by understanding and describing the phenomenon of amateur device provision as it relates to well-established clinical practices.

Methods

As a complex social phenomenon, e-NABLE could be evaluated through several frames. In this study, we set out to understand the meanings that participation in e-NABLE holds for its volunteers and clinical professionals' perception of its impact. Through this study, we uncovered the intersection between amateur volunteers' activity and clinical practices, and implications for stronger coordination between both groups.

In order to become attuned to the context of e-NABLE, the researcher observed multiple venues, including: the online e-NABLE Google+ community and e-NABLE's open-invitation web conferencing meetings; these included a general "town hall" meeting, and other meetings of research and development groups.

We recruited participants for early interviews by posting an online questionnaire in the Google+ community. We conducted interviews with fifteen e-NABLE community members and clinicians. To analyze the themes uncovered during interviews, we applied constructivist grounded theory (Charmaz, 2014).

Grounded Theory

The family of methods within "grounded theory" has been increasingly used in HCI research as "a rigorous way to explore a domain, with an emphasis on discovering new insights, testing those insights, and building partial understandings into a new theory of the domain" (Muller, 2014). We selected a grounded theory method as the basis for interpreting the data in this study because grounded theory affords a means of ordering phenomena, accounting for those phenomena in a system that is based in the data (grounded), and calls for the construction of a description of the phenomena that is systematic, iterative, and rigorous. An example diagram of a grounded theory process can be seen in Figure B2.

There is no single “grounded theory method,” so we refer to grounded theory as a family of methods. The simplest division between styles of grounded theory is Objectivist and Constructivist. Objectivist Grounded Theory assumes a concrete external reality, data that is discovered, and a neutral, passive, authoritative observer. Constructivist Grounded Theory assumes the existence of multiple valid realities and the mutual interactive *construction* of data between the researcher and participants. Rather than an impartial observer, the researcher's values, priorities, positions and actions affect the interpretation of the data and the construction of the theory (Charmaz, 2014).

Initial coding, or open coding, is the researcher's first pass at interpreting the meanings encoded in the textual data. Charmaz recommends focusing on gerunds (e.g. “being sent away” as opposed to “hospital transfer”), because focusing on gerunds will uncover processes and actions rather than a catalog of flat themes. An example of initial open coding appears in Table A2. Charmaz encourages the researcher to continually look for places where the codes indicate missing data, and to gather more data to fill in the missing holes, code again, write memos about the emerging story, and repeat as needed.

Memo-writing refers to the researcher writing informal analytic notes-to-self. Charmaz maintains that memo-writing is an essential opportunity to pause and consider the connections and implications between the properties of the phenomenon under study. Writing memos frequently keeps the researcher involved in the process, and helps increase the level of abstraction of the emerging ideas.

Focused coding is the second major phase for making sense of the data. Codes that appear more frequently, or have more significance than other codes, may be retained in the focused coding stage. The researcher must make decisions about "which codes make the most analytic sense to categorize the data incisively and completely" (Charmaz, 2014).

Over the course of this study, we conducted interviews, transcribed each interview immediately after it concluded, and applied open codes to the transcribed text. We made an initial grouping of themes that seemed to be emerging, and wrote personal journal entries about what seemed to be going on in the study and what data we might gather next. We continually read the posts in the e-NABLE online forums and news articles that related to limb difference, assistive technology, aesthetic customization of AT, and other adjacent topics. We recruited participants for additional interviews, coded their interviews, and wrote more journal entries. Over the course of the study, we refined and adjusted the codes with the goal of succinctly and accurately representing a coherent phenomenon. Several potential phenomena emerged. After careful analysis, we discerned the most coherent of these candidates, at this point in time, to be the interrelationship between amateurs and professional caregivers in DIY upper-limb AT.

Data Sources

Google+ Community.

Although this study included observations of the e-NABLE Google+ community—including web conferencing meetings—the community requires participants to sign in, so it is not a public data source. For reasons of research ethics, we do not quote directly from the community. However, the time spent in conversation with participants and reading the online forums provided background context to the analysis of data obtained in personal interviews.

Online Questionnaire.

To gain a broad understanding of the backgrounds and experiences of volunteers in e-NABLE, we posted an invitation in the Google+ community to complete an online questionnaire (Appendix F). All community members were invited to respond.

We polled respondents on their occupation, the length of time they had spent in e-NABLE, their self-identified role(s) in e-NABLE, their background and experience with 3D printing, general challenges they may experience as a community member, and their perception of the benefits of participation. The community had approximately 4,000 registered members when the questionnaire was issued, but the number that were active participants—defined as, at minimum, reading community posts—could not be readily measured. Sixty-three individuals responded to the questionnaire.

A summary of online questionnaire responses appears in Appendix C. Twenty-nine respondents not only self-identified as fabricators, but also reported that they had printed at least one assistive device. Thirty-nine respondents, or about 63%, reported that they work in a STEM-related occupation (science, technology, engineering or math). Four respondents reported that they work in healthcare, six were retired, and 13 were in other non-STEM professions (e.g. librarian, student, or self-employed).

Interview Participants.

To gain insight into the skills and perspectives of e-NABLE community members and clinicians, we requested interviews with a subset of questionnaire respondents. Following the coding and analytic process described by Charmaz (2014), we selected participants for interviews. We conducted the first few interviews with local volunteers who indicated that they had not made any AT yet, but wanted to do so. This allowed us to test our interview protocols and practices before moving on to interview subjects who were more skilled, harder to find, and required more skilled care and attention to conducting interviews well.

Overall, the researcher conducted 18 interview sessions with 15 individuals. In order to maintain anonymity, each participants was assigned a code identifier (Table A1).

Whenever possible, we conducted interviews face-to-face in the setting where each participant performed their volunteer or clinical work. We prioritized privacy over a natural setting, however. If we could not speak to the participant alone, the interview took place in a neutral location, such as a conference room. Eleven interview sessions could be conducted face-to-face, thanks to interviewees' ability to come to RIT. We conducted five interviews over web conferencing or by telephone. The researcher recorded and transcribed a total of 12 hours, 32 minutes of interview data over a period of five months. The average length of an interview session was 58 minutes. Table A1 summarizes the participants' roles in e-NABLE, demographics, and professional backgrounds.

Coding and Analyzing Data

Throughout data collection, the researcher summarized elements of qualitative data as brief codes and refined the evolving set of codes based on emergent themes. We continually sought to answer the basic analytic questions reiterated by Charmaz (2014), including: "What's happening here? What meanings do different participants attribute to the process [of participating in e-NABLE]?"

The author was the sole coder in this study. We strengthened the validity of findings by member-checking (sharing developing interpretations with participants), performing coding immediately upon transcribing interview data, and keeping a reflexive journal with analytic memos throughout the study as recommended by Charmaz (2014).

First, the author generated a set of initial open codes (Saldaña, 2015) based on transcripts of early interviews. From these, we established tentative themes for exploration. The researcher continued to write analytic notes based on the themes that seemed central to describing the phenomenon. In order to reveal underlying social processes and negotiations, the researcher coded the data with process codes (Charmaz, 2014); generally, these were verbs ending in -ing. Examples of representative process codes include "helping a user relate to their device," "using personal funds," and "seeing smiling faces."

We identified focused codes: codes with high "carrying capacity," or potential for useful analysis. A useful method for discerning analytic codes was given by Saldaña (2015): the "touch test." Tangible artifacts are less analytic than descriptive. If a code represents something "touchable," it is more likely to be descriptive than analytic. For example: a prosthetic device is touchable, and thereby less interesting for analysis, but the *process of selecting* a prosthetic device has high potential for analysis.

The interview excerpt in Table A2 provides an example of open coding. At the initial stage, the researcher attempts to capture the essence of the idea in each fragment by constructing a brief, descriptive tag, or open code.

Constructivist grounded theory is not a theory, but rather a method used to construct theory. "Theory" refers to a set of tested general propositions that can be used to explain a class of phenomena. Due to the limited scope and period of time allotted to this study, we constructed analytic categories, but did not carry analysis through to the construction of theory (Charmaz, 2014).

Tools and Processes

We used a hand-held voice recorder to capture interviews, both in-person and over speakerphone. We took field notes during each session. We transcribed each recording by playing it back at half-speed while wearing noise-canceling headphones in a quiet location.

Initially, we used Saturateapp (http://www.saturateapp.com/) as a software tool for qualitative data analysis. After creating 177 initial open codes, and upon trying to group similar codes together, we found Saturateapp unwieldy to work with. We ported the data and codes-in-progress into Dedoose (http://www.dedoose.com/), which allowed for creation and combination of codes, generation and sorting of memos, and export to Excel for further sorting, integration and analysis.

Operational Logistics of e-NABLE

The following is a description of e-NABLE as the field site of this study. Although the goal of an analytic study is to rise above the level of simple description, it is necessary to have an overview of e-NABLE's roles, structures and processes in order to interpret it as a social phenomenon.

The e-NABLE Project

Here we provide a description of the virtual "field site" of this study; the e-NABLE community and its work products. e-NABLE is a worldwide group of volunteers who design, modify, produce, and deliver 3D-printed assistive technology to people with upper-limb differences. e-NABLE's online presence is spread across various websites and forums, including a main website (Enabling, 2015), a private Google+ community (Google+, 2016), a separate forum for research and development (Forums, 2016), and various other social media accounts. e-NABLE's members exchange open hardware source files, advice, and support around this form of digital humanitarianism. The main locus of activity at the time of this study was the Google+ community.

e-NABLE's web site characterizes its mission as "To enable any child or adult to receive a free or very low cost experimental upper limb prosthetic," (Foundation, 2016) and as "a global network of volunteers who are using their 3D printers, design skills, and personal time to create free 3D printed prosthetic hands for those in need—with the goal of providing them to under-served populations around the world" (Foundation, 2016).

The wide availability of design files, across multiple formal and ad hoc distribution channels, imply that statistics on the number of devices delivered to end users is difficult to track. In an interview in this study that took place in 2016, one community organizer estimated at least 1200 direct deliveries of a device to a recipient had taken place, with perhaps the same number again printed by anonymous fabricators.

The Online Community

The online e-NABLE community is primarily situated in a private Google+ community (members must request to be admitted). Whereas the community had 4,000 members when we issued the online questionnaire, by May 2016 it had grown to over 8,400 members, and it continues to grow.

Potential recipients and parents of recipients participate in the community discussions, alongside general 3D printing hobbyists who are interested in volunteering. Medical professionals, clinicians, and orthotists/prosthetists occasionally lend their expertise to community discussions.

We observed members of e-NABLE carrying out various forms of collaboration and communication on both the Google+ (Google+, 2016) and separate phpBB forums related to research and development (Forums, 2016).

General classes of postings included:

- Media stories about fabricators and recipients
- Fabricators posting questions about current obstacles
- Fabricators showing their completed, or in-process, builds
- Recipients requesting a device
- Recipients or fabricators showing devices with recipients
- Designers debuting new designs
- Community organizers advertising upcoming local events

- Community organizers requesting unassembled hand kits for group assembly at conventions and events (“Hand-a-Thons”)
- Postings about new materials and techniques for fabrication
- External blog posts featuring e-NABLE or its related devices

Roles in e-NABLE

Volunteers in e-NABLE can elect to take on one or many of a wide variety of roles. As listed on the volunteer intake form (Appendix D), these include: blogging, developing, writing documentation, fabricating devices, matching between fabricators and end users, photography and videography, coordination/organization, training, and document translation. Many people consider themselves part of e-NABLE even if they do not have an explicit role. 13 out of 63, or 20.63% of respondents to this study's online screener survey (Appendix F), self-identified as a “spectator or fan,” as shown on Table A5.

e-NABLE's “development” role comprises more of an engineering than a programming focus. Developers, or designers, collaborate on adapting or creating new functionality, evaluating and improving the printability of devices, and determining better ways to work with the various 3D files involved in each project.

The most visible volunteer role in e-NABLE—most prominent in e-NABLE’s promotional materials—is the fabricator. The fabricator role exists because the organization depends on converting the digital device designs into tangible objects that can be delivered to end users. Fabricators donate their time, and often their personal funds, to pay for filament, hardware and postage.

The fabricator role is distinct from device designer/developer: the designer/developer carries out 3D modeling, creating new printable AT, whereas the fabricator interacts with recipients, personalizes the 3D models, prints and assembles the device, and delivers the final form to the recipient.

STEM refers to the subject areas of science, technology, engineering and mathematics. The STEM-related backgrounds of fabricators may bear on their ability to successfully create complex 3D-printed devices with moving parts. As shown in Table A3, respondents to the online questionnaire who successfully fabricated devices tended to come from professions such as computing and engineering.

Clinicians as they relate to e-NABLE.

Among the 14 roles listed on the e-NABLE volunteer intake form (Appendix D), none of them include prosthetist, orthotist, medical professional, or clinician. During our time reading new posts in the e-NABLE online forum, a few self-described medical professionals or students of prosthetics introduced themselves and expressed a desire to help in some way. Over time, we did not see evidence that these resulted in concrete ways to help. This made us curious to explore the relationship between professional expertise and amateur prosthetic device provisioning. Therefore, we included clinicians among our interview subjects.

e-NABLE Devices

There is no single “e-NABLE device;” rather, the e-NABLE community uses a constantly-evolving array of upper-limb assistive devices, as seen in Figure B3. All of the devices shown have the mechanical affordance of providing a basic grip, and the cosmetic quality of appearing somewhat like a human hand. An example of a typical wrist-powered device is depicted in Figure B1.

e-NABLE's fabricators produce several types of devices that allow a simple grasping motion, using a set of cables to cause the fingers to contract. When the recipient has a sufficient

remaining palm and range of wrist motion, bending the wrist actuates the device.
e-NABLE commonly refers to wrist-actuated devices as “hands.” e-NABLE's designers have developed arm designs that use the recipient's elbow as a point of flexion, as well. They are also investigating alternative points of actuation, including shoulder movement for users whose residual limb terminates above the elbow.

e-NABLE has a beta testing process for validating candidate device designs, which is documented in the online community. This device validation process includes selecting an appropriate open license, documenting assembly instructions, drafting a bill of materials with sources for all non-printed parts, documenting the results of print tests and user tests, and determining a support plan for questions that may be generated by users.

When a device design is approved for wide release, source files are posted to a publicly-accessible repository, such as Thingiverse (UnLimbited, 2016), Youmagine (Holmes-Seidle, 2016), or github (Price, 2015). A link to the design is added to the list of devices on an e-NABLE website (http://enablingthefuture.org/upper-limb-prosthetics), and announcements of the new design are posted to the Google+ e-NABLE community.

Although 3D printing is used to producing the main portion of each device, many designs also include a significant portion of non-printed parts. These can include rubber bands, durable screws, hook-and-loop fasteners, foam padding, leather, and/or soft fingertips. Not all of these components are commonly available in all regions of the world.

Matching a Fabricator to a Recipient

The official process for allowing a fabricator to work with a recipient is described on the Enable Community Foundation webpage (Foundation, 2016). First, potential fabricators are asked to print out a “test hand” and send it to the matching team for evaluation.

V11, a volunteer coordinator in e-NABLE, describes the history of this process: “Originally [our approach] was “if you want to be matched, we'll match you.” And then we started seeing that there's skill levels. Not everyone can step into it and make a hand the first time. So we started a test hand process where everyone has to create a test hand, submit it for approval, before they're actually matched to the family. Because being assigned to a family and thinking you're doing something good, and having it lead to disappointment when you can't provide the hand that they're asking you for, is just not good for anyone. And so this gives them a chance to work the kinks out of things before they're ever assigned to someone.”

V11 noted that this “test hand” exercise can also allow a casual fabricator to find out whether they like the work of volunteering without ever jeopardizing the good will of a recipient or a family: “And plus, you know, there's sometimes a novelty factor. They see great stories in print and on TV, and they're excited to sign up, and they want to make that one hand, but they don't necessarily really want to stick around. So sometimes the test hands meet that need. And it kind of filters out the ones that are long-term or not, rather than assign them to someone and have them walk away because they're too busy, or whatever.”

New fabricators, eager to begin working with recipients, often ask in the community where they may send their first assembled devices to be validated by the e-NABLE community. When a recipient is not available to be matched to a willing fabricator, the e-NABLE matching team often suggests instead that they instead produce hand kits for assembly events, known as “hand-a-thons” or “make-a-thons.” These assembly events allow low-skilled novice fabricators, such as scouting troops, to experience the satisfaction of assembly without having to deal with the learning curve of 3D printing.

Sizing and Fitting

Once a specific recipient is known, the device design must often be customized to better fit its intended user. In cases where a fabricator is geographically distant from the recipient, the process of measuring the recipient's residual limb can present a challenge. Zuniga et al. (2015) proposed the current recommended practice in the e-NABLE community. The recipient provides the fabricator with three top-down photographs from different angles of the affected limb(s) with a reference object for scale. The fabricator uses these photos to calculate measurements that they can use to properly modify (size and scale) the device design files.

The recipients' ability to produce good-quality photographs is not guaranteed, however, as the accuracy of their measurements can be affected by non-orthogonal viewing angles and can suffer from lens distortion at close distances. The prospect of taking 3D scans of the residual limb has been discussed in the community, but this presents its own difficulties. 3D scanners are relatively uncommon, expensive, and difficult to use. They measure the surface of the limb, leaving internal structure unknown to amateurs. Scanner output is not always readily importable into 3D design software. All of the fabricators interviewed in this study used a photo measurement process, but one disclosed an additional method. V08 described asking a parent to mail him an outline tracing of the recipient's affected palm area.

The next step in the fabrication process is to customize the design files. Because each individual’s limb is different, simply scaling the model is not sufficient. The area of the device that attaches to the arm must be modified to fit, and the overall device must be an appropriate size and weight for the user. An arm-sized device requires more extensive sizing than a hand, due to the greater variation in size of the forearm. Fabricators normally use 3D modeling software for these tasks; this can be challenging for novice designers, especially those using low-cost, simple software such as TinkerCAD. The simple scaling functions supported by free software are not well-suited to complex sizing tasks; for this reason, some advanced device designers use software such as Fusion360.

V08 described another technique for conducting remote sizing. Instead of printing the entire device with moving parts, V08 printed and sent only the palm section to the recipient: "So I could get feedback, saying `Do you think this is going to fit, before we go ahead with the whole build?' So as opposed to printing a whole extra hand and sending it, you know… e-NABLE can just mail out a cheap palm, which is 2 dollars in plastic, and we can get a lot of information just from that."

In addition to size adaptations, many fabricators seek advice on modifying design files to fit the unique geometry of the end user's limb. Variations include recipients with nonfunctional fingers, those who have a functional remaining thumb, and adults for whom a simple scale-up of child-sized designs would not be appropriate.

Findings

The following themes emerged from the process of coding and analysis described in Methods. Taken together, these themes outline a nuanced set of perspectives from volunteer makers and clinical professionals. These findings involve the motivations of stakeholders, the skills they bring to bear on this activity, and their perceptions of risk to end users. Participants in this study also hinted at promise that future directions in this domain may hold for improved user outcomes.

Findings are briefly summarized as follows. Makers are motivated to volunteer by a desire to help and a desire to use their technical skills. Clinicians are motivated by, and constrained by, a professional ethic to “do no harm.” Volunteer makers and clinicians have different skill sets, but they are potentially complementary. A prominent benefit for end users is the increased ability to personalize devices through customization, aesthetic or otherwise. There is an apparent gap involving obtaining feedback from end users.

Finding 1: Volunteer makers derive personal benefits that are both altruistic and reflexive

For makers, the motivation for participating in e-NABLE involves both the ability to make a positive difference in someone else's life while simultaneously proving and/or developing technical skills. This is consistent with the known volunteer motivations of collective and reflexive volunteering (Hustinx & Lammertyn, 2003).

V04, a mechanical engineering student, related her experience of personal development: “It has actually been really rewarding. I've learned and grown in my engineering skills, in my innovation skills, and also just in how I can approach a problem and break it down. I feel more confident in my skills, even though I know I still have a lot more learning to do.”

V02, a retired human factors engineer, explained that he derives personal benefits from solving unique puzzles: “For me, personally, there's some kind of a self-esteem satisfaction related to solving a problem that nobody's ever solved before, creating something that nobody's ever seen before. The more difficult it is to make something work, the more excited I get, because the more likely it is that other people have given up before they solved all the problems. And probably it's never been done before.”

V08, a member of the 3D printing industry, described some of the unexpected professional benefits of volunteering through this form of making: “It's rewarding in the fact of the people I meet, the places I get to go… the networking that I've had, the publicity that I've had, that's all been very rewarding. I've been able to shake hands with some fairly important people just because of the work that I'm doing with e-NABLE.”

V04 expressed both aspects of personal benefits to makers: improving one's own skills while doing good. V02 noted that there is an additional thrill of doing something that few are able to do: for V02, to “solve new puzzles.” And for some, such as V08, there are “soft benefits” that include professional networking.

Finding 2: Clinicians' motivations are based in the principle “do no harm”

For clinicians, the motivation to participate in e-NABLE, even in limited ways, is to reduce the harm to end users.

C03, a prosthetist, had explained that she perceived early e-NABLE devices to have far less durability than traditional prosthetic devices. She explained the external motivators to prioritize patient safety when faced with the typical e-NABLE device: “We do have a “do no harm” principle. Just like all medicine does. We don't believe in [3D printed grasping assist] devices. There's a liability issue, because of the durability. We would not put something on somebody that was that fragile. It's a liability problem."

For C01, an occupational therapist, harm reduction meant taking part in the online e-NABLE forums to provide critique of methods and devices:

"I wore one device that I tested that I broke within seconds. The first thing I tried to do was use a hook grasp to pick up a 5 pound backpack that had one book in it. One of the little joints around the fingers snapped." C01 continued, "As with any new technology, it's not miraculous. There are some major flaws, and that's my role as I see it, to be the "bad guy," pointing out the flaws, that we can make these amazing devices even better."

C02, a student of orthotics and prosthetics, also found providing critique to be a natural-feeling way to participate in e-NABLE. She related that being the bearer of bad news is not fun, though: "I feel kind of bad sometimes because I'm such a "Negative Nelly," I guess, because I have to worry about [patient safety issues] in my future career, and I'm worried about them now. That's kind of why I'm the devil's advocate here sometimes, because I'm like "well, we've got to think about these things and then we've got to find the solution." I know people want to make the cheapest thing they can, the most affordable thing they can, but sometimes that's not what people need."

"Do no harm" is the first consideration for clinicians, both for reasons of end user advocacy and for professional liability. The three clinicians we spoke with felt most comfortable limiting their contributions to the level of providing critique of the e-NABLE devices and methodology. They tried to temper e-NABLE's celebration of disruptive making with a dose of reality, giving the needs of end users the highest priority.

Finding 3: Makers and clinicians possess different, but complementary, expertise

Makers and clinicians have similar motivations to use their skills to help people with limb differences. Their differences center on their attitudes about risk.

V02, a volunteer designer and fabricator, admired clinicians' deep knowledge of anatomy: “And so it's a tougher thing to do to make a design that is safe for people with less training than a prosthetist gets, you know, years of school after college, and internships and all of that. Clinical experience. We engineers that are doing this, we don't have clinical experience, typically.”

Clinician C03, in turn, admired the makers' ability to rapidly prototype one-off devices. They noted that the clinical infrastructure depends on devices that have enough of a market to be manufactured at scale: “The thing [I admire] is their ability to rapidly prototype things, and to make just one of something. Unless we're machining it in our shop ourselves; [but] few people have the ability to do that to any great degree. We can make a lot of things out of plastic, but we mostly have to thermoform them and grind away to get a printing kind of [end result]. And manufacturers are not going to make one thing for one person.”

V12, a CAD designer, highlighted the difference, and potential complementary overlap, between clinical skills and 3D printing/design skills: “…the primary role that the prosthetist plays in the process, is using their very trained eyes and the sum total of their training, to assess what is and isn't appropriate. My experience, as a designer … is to choose structures to be more optimized for the printing process.”

Makers show evidence that they know that their expertise has limits. V02 admired the anatomical expertise of clinicians and their ability to ensure a good fit. C03, in turn, admired makers' relative freedom to experiment and to go deeply into one-off designs. Those are luxuries afforded to amateurs who are not bound by safety concerns or market realities. V12 summed up the overlaps between makers and clinicians: clinicians bring in their “very trained eyes and the sum total of their training" to know what will work well for a patient. Designers and fabricators, for their part, are experts in knowing how to optimize devices for printing and assembly. By knowing one another's skills and recognizing their own limitations, clinicians and makers do have the ability to make a positive impact for end users.

Finding 4: The positive impact for end users involves increased aesthetic choice

Even more than function, the main positive impact for end users is the ability to have some control over the aesthetic presentation of their affected limb. The e-NABLE devices are simple grasping assists. They are not highly regarded by clinicians for their functional properties, as C03 noted: "The technology for doing the e-NABLE wrist-driven devices has been around for a long time. There's a reason it's not used a ton. There are some limitations in that design, which is another reason why how popular these were and the amazing response [from the public] was so surprising. In [clinical] practice, you don't get [a positive] response from those devices, for the most part."

C03 contrasted the patient response to wrist-driven devices with other, more functional designs, such as hooks. She explained that hand-like terminal devices are more bulky, and grip force tends to be less, but they can have cosmetic appeal.

V08, a volunteer maker, described his understanding of the experience of a child with a limb difference: "A lot of it is, once they start getting older and get out of the house, they start going to school, they start getting on the bus, and they're put into a world where all of a sudden they're different, where they're bullied, where they're singled out. The hands, to me, you know, there's a little more psychology involved that they can wear something that makes them feel unique, that makes them feel special, you know, it's a superhero hand; it takes it from them being bullied to them being the cool kid in class." Such a "superhero hand" is depicted in Figure B4.

V09, a limb-different fabricator, described the ability to influence the reactions of passersby as his main benefit of wearing a device: “I've spent most of my adult life hiding my disability, putting it in my pocket, hidden away. But when I didn't hide it away, I would normally get lots of children and adults pointing and staring and whispering. Now instead of that, what I tend to get is people looking at the 3D printed arm, and walking past and going “wow, cool!” It gives you an opportunity to start teaching them about e-NABLE. Instead of pity or ridicule, it's more “wow, that's cool!”

e-NABLE represents a capability, heretofore unavailable to end users, to have a high degree of input into the aesthetic presentation of their upper-limb device.

Finding 5: There is a gap in obtaining feedback from end users after delivery

Although end users can specify the aesthetics of their devices, it is not clear whether the end result is a device they use every day, or a seldom-worn novelty. While e-NABLE may be making a positive difference around end user choice, it's difficult to measure the extent of that impact. End user feedback has not thus far been obtained in a systematic way.

V12 perceived a risk that e-NABLE prioritizes the feelings of the volunteer fabricator, assuming a needed and positive impact on end users: “I think the danger of the work we do with prosthetics, and with kids in particular, is that it's a story that sells itself. It can actually have almost no substance. But it just bypasses most of our intellectual filters and hits the heartstrings hard. It's very easy to get caught up in it and not ask those hard questions, like “did I actually help this kid? Is this kid going to actually use the device in a week, in a month, two months? What happens when it breaks? What do they actually want to do with it?”

C03, a clinician, underscored the need for long-term follow-up in any system of care that involves providing devices. The needs of end users will change over time: “One of the reasons why I think there is the impression that people are a lot happier than I would assume they are is because if they go home and don't use it, no one's going to know. In the opinion of the upper limb experts, the only way to have a successful outcome is to have that long term follow-up. Because things are going to change. People are going to encounter things they didn't expect after they leave our office."

V07, a fabricator who sends devices to South America, confirmed that after he delivers a device, he seldom hears any feedback: "I haven't been notified about [the need for repairs or updates], and it's kind of one of the concerns of whether they would be embarrassed to ask. They were so grateful to be able to get something for them, and I made sure to make them aware, you know, "I'll be glad to send you an STL [object] file if there's somebody there that could fabricate it, or, you know, just tell me what's broken and I'll send you another one."

Several other fabricators reported similar instances of communication with recipients slowing, or stopping, after the moment of delivery. It is not clear whether this is due to fabricators' reluctance to intrude on recipients, or to recipients' reluctance to bother fabricators, both, or another cause entirely.

It is not possible to describe the impact of e-NABLE without a systematic measurement of its effects on end users. Given that it is well-established in literature that the needs of users change over time, a program for gathering user needs should be central to any effort that attempts to have authentic impact. An opportunity exists to systematically gather user needs before device provision, and to follow up with users to determine the fit of devices with their functional and psychosocial needs.

Discussion

On the surface, e-NABLE appears to be a simple scenario: when an end user requests an assistive device, the organization pairs them with a volunteer maker who fabricates and delivers a device to that end user. On closer inspection of particular cases, however, a host of questions arise: Are the devices addressing a need for the end user? If so, which need? Is the prosthetic function aesthetic, functional, social, or a blend of all? Do these devices impart benefits to children by smoothing over the social stigma of limb difference? Do they reinforce ableist assumptions that a limb-different child must be made symmetrical? How much input do end users have into the design decisions in each case? When end user input is not measured, do volunteers risk framing a recipient as an engineering problem to be "fixed?" What is the actual impact, over time, of this design intervention? How much of e-NABLE is a Western world phenomenon, and what generalizes to other economic and cultural contexts?

Recognizing that we cannot address the entire nuanced multi-dimensional problem space of e-NABLE, we limited the scope of this study to investigating the nuance around the interplay between volunteers and clinicians. We found, in interviews, that e-NABLE volunteers and clinicians share similar values and motivations: to use their skills to help people. They differ in their work settings, however. Whereas many e-NABLE volunteers perform their work remotely for recipients that they may never meet, clinicians provide assistance face-to-face with patients on a one-to-one basis. Despite the distributed nature of e-NABLE, volunteers were driven by the idea of helping an individual.

These common motivations, however, do not necessarily imply common work practices. Clinicians are constrained by the practical realities of their profession, including economic and medical issues. Therefore, clinicians we interviewed were more inclined to use their expertise to provide opinions in e-NABLE's online discussion forums rather than get involved with direct care delivery to recipients. Volunteers, by contrast, were not inhibited by perceptions of liability. They acknowledged their shortcomings as care providers, and trusted that end users would eventually seek the assistance of a clinical professional.

Both volunteers and clinicians possess advanced skills. Makers' skills are focused on rapid prototyping and amateur fabrication. As demonstrated by posts in the e-NABLE forums and validated through interviews, e-NABLE's volunteer makers are inclined toward experimentation, technical iteration, and process improvements around 3D printing. Clinicians also have some small-scale manufacturing expertise, as with thermoforming, but are much more focused on patient safety, and so their perspectives evince a guarded stance toward untested methods. Clinicians also have a deep set of “soft skills” related to patient counseling, needs gathering, and empowering end users to make their own decisions about their care. The skill sets of makers and clinicians should be complementary, as they have the common goal of helping end users. The challenge lies in negotiating the trade-offs between the distributed engineering skills of engineers and the local, in-person methods of clinicians.

There is a lack of concrete information about how e-NABLE devices are used after delivery. Both volunteers and clinicians are aware of this gap, and both groups suggest that recipients should be encouraged to engage with clinicians in a long-term clinical care relationship. There may yet be technological solutions to this gap in usage data. We describe a potential means of addressing this gap in the next section.

Volunteer makers we interviewed acknowledge that there are risks involved with the devices they make. They can imagine ill effects including breakage, injury, and overuse, but our interviews with clinicians have revealed a larger set of risks that volunteers are not aware of.

Clinicians also consider strain on the limbs and overuse of the unaffected limb, and they consider each patient's case within the context of the health care infrastructure. While clinicians feel safe providing critique in the e-NABLE forums, it's not clear that this feedback is being taken to heart by amateur makers. Conversely, amateurs have expressed frustration at clinical expertise being locked up in journal publications. An opportunity exists for clinicians to package some of their knowledge of effective practices for the volunteer audience. Indeed, if the parents of affected end users continue to approach volunteers for help instead of clinicians, volunteers may be best-positioned to educate those parents on the landscape of care options.

Recommendations for Design

We have described a recently-possible form of assistive technology acquisition: people with upper limb differences being able to request low-cost prosthetic devices from volunteer fabricators. Our findings identified areas where amateur makers' motivations, skills and perceptions of risk diverge from those of traditional professional clinicians. As with many social phenomena, the e-NABLE community has many potential areas for technological support, but resists quick and easy solutions. We briefly sketch a few potential ways that e-NABLE might sustain its momentum while increasing measurable positive impact for end users.

We suggest four areas for potential future exploration: cross-cultural education between clinicians and makers, platforms for case management, improved tools for co-design, and instrumentation of devices to enable quantified usage data.

Clinicians Educating Makers, and Makers Educating Clinicians.

Fabricating devices requires maker-volunteers to learn about 3D printing, mechanical engineering, 3D CAD tools, and shipping logistics. Our interviews with clinicians revealed that prosthetics care involves a subtler, and deeper set of skills. Helping a patient make an informed decision necessitates being fully informed as a care provider and using non-technical skills that were not evident in our interviews with volunteer makers. As e-NABLE grows, there may be ways to harness volunteers' desire to help in the service of educating the parents of children with limb differences. Parents who approach e-NABLE may not be familiar with the clinical background of prosthetic care, and share current volunteers' perception that care consists of dispensing a device. A sufficiently educated volunteer, grounded in a subset of clinicians' knowledge, could provide some measure of counseling to those parents in order to increase the chance of an informed decision, and thereby a stronger end user impact. Similarly, clinicians have expressed that they would like to know more about amateur fabrication methods. The opportunity exists for a reciprocal exchange of knowledge and customs, and we may imagine a range of technical knowledge support systems to enable that exchange.

Support Systems for Case Management.

In the case of fully-distributed volunteering scenarios, when end users are distant from fabricators, current communication practice seems limited to email and web conferencing applications such as Skype. Further, apart from matching recipients to fabricators, there is scant evidence for e-NABLE tracking the status of cases-in-progress. After the match, fabricators are left to deliver, or not, according to their own judgment and their own processes. There exists an opportunity to standardize and track the status of cases-in-progress through a support system designed for case management. Processes can be standardized, from early phases (needs discovery, end user requirements gathering) through to iterative design, delivery, and crucially, procedures for follow-up after delivery. Such a system would provide recipients with a firmer footing for making informed choices, being aware of potential risks, and increasing the likelihood of successful outcomes.

Platforms for Co-design.

Because each user's needs are highly specific to their circumstances and greatest perceived needs, each instance of customized AT represents an opportunity to design a unique device. But design benefits from a sustained, interactive dialogue between user and designer. Although one of the areas where e-NABLE shines is aesthetic customization, none of the fabricators we interviewed mentioned engaging in long-term iterative adjustment of devices with recipients.

A support system would enable volunteers to gather needs from recipients and iterate in tight feedback loops throughout the design of a device. Recipients would provide feedback around aesthetic, functional, and other aspects of devices, and the volunteer maker(s) would use their technical and artistic skills to realize the device. Any such system would have to attend to privacy and the age of recipients, with appropriate oversight by parent/guardians.

A second area of opportunity for co-design involves partnership between volunteers and clinicians. This direction depends on the availability of a clinician in the hypothetical scenario of care. This type of platform for co-design could enable volunteer designers to contribute to the CAD design of whole new devices, or just to components such as task-specific end effectors. Clinicians could contribute by vetting those designs and identifying risks and safety concerns. Or, as suggested by Hofmann et al. (2016), clinicians could contribute well-fit sockets in a given case, and volunteer makers could contribute personalization as specified by the end user. Such a collaborative, cross-functional approach would allow volunteers to maintain the direct relationship with recipients that is bound up with their motivation to volunteer, while also satisfying the clinicians' motivation to contribute safety expertise to meaningful solutions for recipients.

Quantified Usage Data.

The lack of information about outcomes in e-NABLE echoes a general challenge in prosthetic device provision: follow-up with end users currently requires users to stay in close contact with clinicians. Because each e-NABLE device is a manufactured artifact, it is possible to include sensors on or within the device itself. Such a system would provide finely-detailed data about device use patterns. If a device stops sending data, that could be a trigger for a volunteer to reach out to the end user for feedback. Sensors and signaling systems are available at small enough sizes, with low power consumption, to allow for such devices as accelerometers, gyroscopes and Bluetooth to be included in body-worn devices. By using such sensors, whether designed *de novo* or using a repurposed smartwatch, researchers could obtain rich data on the ways e-NABLE devices are used.

Limitations

This study is a snapshot in time of e-NABLE as it was described by a set of stakeholders in the period 2015-2016. The community continues to grow and evolve. Our research represents the attitudes, opinions, skills, motivations, and goals of a subset of community members at a specific moment in time. Some current bifurcations of e-NABLE, for example, attempt to move away from the “distributed amateurs from the Internet” model toward a more centralized, in-person method of device provision, guided by clinicians and non-governmental organizations (NGOs).

As with any study that depends on consenting participants, our results reflect self-selection bias. The perspectives of participants who are willing to participate in a study are necessarily over-represented in relation to those who would prefer to keep their views private. The clinical perspectives, in particular, may diverge from those of clinicians who have chosen not to be involved with e-NABLE. Future research would benefit from widening the spectrum of voices and perspectives to further elucidate the dynamics in play in the phenomenon of rapidly-fabricated amateur AT provision. While we learned a much about the perspectives of clinicians as they relate to fabricators' capabilities, the voice of the recipient is notably absent. In future work, we would examine the perspectives of limb-different end users and their families. We would seek to learn about end users' intended uses of prosthetic devices, how those uses are addressed by traditional means, what e-NABLE affords that traditional provision methods do not, and the extent to which end users want to be involved in the design and provisioning of devices.

Conclusion

In this study, we have described e-NABLE, a group that organized around the cause of providing personalized, low-cost assistive technology to limb-different end users. We presented the themes uncovered through interviews with a sample of stakeholders comprised of volunteers and clinicians. We analyzed the overlaps and disconnects between these stakeholders' motivations, skills and perceptions of risks. Although this study focused on e-NABLE, our findings may bear on other volunteer efforts that involve production of physical devices for remote recipients, as well as volunteer communities that involve amateurs performing tasks traditionally performed by experts.

We found that both groups are motivated to help people, but either constrained (as with clinicians) or disinhibited (as with makers) by their disposition toward risk. We posit that the skill sets of clinicians and makers are complementary, so long as they are centered on the end goal of helping end users navigate their needs. At present there is an uneven distribution of knowledge and practices between these two stakeholder groups. As a result, the success of outcomes for end users is difficult to measure.

These findings suggest that there is promise for realizing positive impacts. Future directions may involve closing the gaps in knowledge, skills and participation between clinicians and volunteer makers. Because the skills of clinicians include holistic requirements-gathering, design inputs will be improved when fabrication actors use clinically-informed methods. Because clinical skills include obtaining feedback from end users, future work can involve closing the loop to enable an iterative design process toward continual improvement of relevant, needed assistive technology.

Future work may include building knowledge support systems to help clinicians understand rapid fabrication methods, and to help volunteer makers understand the need for clinical practices. Further, a support system for case management may be designed and implemented. Such a system would track a user who requests a device from needs-gathering through iterative design cycles to delivery and feedback. Similarly, a platform may be designed to enable co-design of devices between a grouping of stakeholders that can include volunteer maker(s), clinician(s), and the end user. Such a platform may either be a complement to a case management system, or an integrated component of such a system. Finally, we advocate for developing means to obtain usage data directly from the fabricated devices, through the use of sensors embedded in prosthetic devices themselves.

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Appendix A Tables

Table 1

Interview Participants

ID	Gender	Age Group	Role(s)	Occupation
V01	F	21-25	Community member	Plastics engineer
V02	M	71-75	Designer, Fabricator	Ergonomics engineer
V03	M	61-65	Community member	Researcher
V04	F	21-25	Designer, Fabricator	Student (engineering)
V05	F	21-25	Designer, Fabricator	Student (engineering)
V06	F	41-45	Fabricator	Student (multidisciplinary)
V07	M	61-65	Fabricator	Information tech. (retired)
V08	M	31-35	Fabricator	3D print shop technician
V09	M	36-40	Fabricator	CAD technician
V10	M	18-20	Fabricator	Student (undeclared)
V11	F	36-40	Community member	Logistics coordinator
V12	M	26-30	Designer, Fabricator	CAD designer
C01	M	31-35	Clinician	Occupational therapist
C02	F	21-25	Clinician in training	Prosthetics student
C03	F	31-35	Clinician	Prosthetist

Table 2

Example of Open Coding

Verbatim Interview Data	Initial Code
Reinventing the wheel. (chuckles) I think a lot of people are just getting so excited, they're not taking the time to do their homework, and I think, you know, "this is awesome, I'm going to get in there and change the world," and, "it fits all these problems that have been plaguing the prosthetic industry for so long!" and… they don't really have respect for the systems that are already in place.	"Reinventing the wheel" "Not doing their homework" Perceiving hubris of makers. Lacking history of prosthetics.
Ah... (sighs) You know, a lot of people say greed. Maybe there's some truth to that. I think part of it is... e-NABLE's not necessarily taken seriously.	e-N not taken seriously.
Part of it may be the old guard being a little technophobic.	Threatened by new tech?

Note: The table above is a representative sample of the open coding process. Working from the transcribed interview data in the left column, the coder has discerned and assigned codes in the right column.

Table 3

Online Survey Respondents' Professional Occupations

Occupation Type	Fabricator (N=29)	Aspiring (N=25)	Non-Fab (N=8)	Total (N=62)	Percentage
STEM-Related	22	15	2	39	62.9
Healthcare	–	2	2	4	6.5
Retired	2	2	2	6	9.7
Other	5	5	3	13	21.9

Table 4

Online Survey Respondents' Length of Time Involved with e-NABLE

Duration Months	Fabricator (N=29)	Aspiring (N=25)	Non-Fab (N=8)	Total (N=62)	Percentage
< 1	1	12	1	14	22.6
1–6	12	10	6	28	45.2
6–12	11	3	1	15	24.2
> 12	5	–	–	5	8.0

Table 5

Online Survey Respondents' Self-Reported Roles in e-NABLE

Role	Fabricator (N=29)	Aspiring (N=25)	Non-Fab (N=8)	Total (N=62)
Device fabricator	29	10	–	39
Community member	10	6	2	18
Prosthetic designer	11	5	–	16
Spectator/fan	1	6	6	13
Software developer	6	4	–	10
Community organizer	3	–	1	4
Clinical professional	–	1	1	2

Note: Respondents were able to select multiple roles.

Table 6

Online Survey Respondents' Relationship to Recipients of e-NABLE devices

Relationship	Fabricator (N=29)	Aspiring (N=25)	Non-Fab (N=8)	Total (N=62)
None known	6	23	3	32
Have met through e-NABLE	21	2	1	24
Know through work	3	–	1	4
Friends or family	3	–	3	6
Self (I am one)	–	1	1	2

Note: Respondents were able to select multiple relationships.

Table 7

Online Survey Respondents' Average Hours per Week Volunteering with e-NABLE

Hours	Fabricator (N=29)	Aspiring (N=25)	Non-Fab (N=8)	Total (N=62)	Percentage
0	–	8	–	8	12.9
1–5	11	14	5	30	49.2
6–10	6	2	1	9	14.8
11–15	5	–	1	6	9.8
>16	6	1	1	8	13.1

Table 8

Online Survey Respondents' Self-Reported Benefits of Participation

Personal Benefit	Fabricator (N=29)	Aspiring (N=25)	Non-Fab (N=8)	Total (N=62)
To be able to benefit others	16	6	3	25
To develop skills/learn	6	7	3	16
Networking with others	4	7	1	12
Outlet for my talent	2	4	–	6
To see smiling faces	3	2	–	5
To use my 3D printer	2	–	–	2
Makes me stand out	1	1	–	2

Note: Open-ended text responses were summarized and grouped by similarity.

Table 9

Online Survey Respondents' Self-Reported Reasons for Making Prosthetic Devices

Reason	Fabricator (N=29)	Aspiring (N=25)	Non-Fab (N=8)	Total (N=62)
To benefit others	27	22	5	54
To help e-NABLE	18	15	4	37
To use or improve skills	19	14	3	36
For creative expression	6	5	1	12
To help friend/family	4	3	2	9

Note: Open-ended text responses were summarized and grouped by similarity.

Table 10

Online Survey Respondents' Self-Reported Obstacles to Fabricating Devices

Obstacle	Fabricator (N=29)	Aspiring (N=25)	Total (N=62)
Printer issues	9	3	12
Scaling/modifying design files	9	2	11
Trying to customize designs for users	6	–	6
Dealing with different file standards	4	–	4
Getting accurate limb measurements	3	–	3
Finding tutorials or information	1	–	1

Note: Open-ended text responses were summarized and grouped by similarity.

Appendix B Figures

Figure 1. A 3D-printed upper-limb assistive technology device (e-NABLE Raptor Reloaded hand design). Photo: Jeremiah Parry-Hill. November 12, 2015.

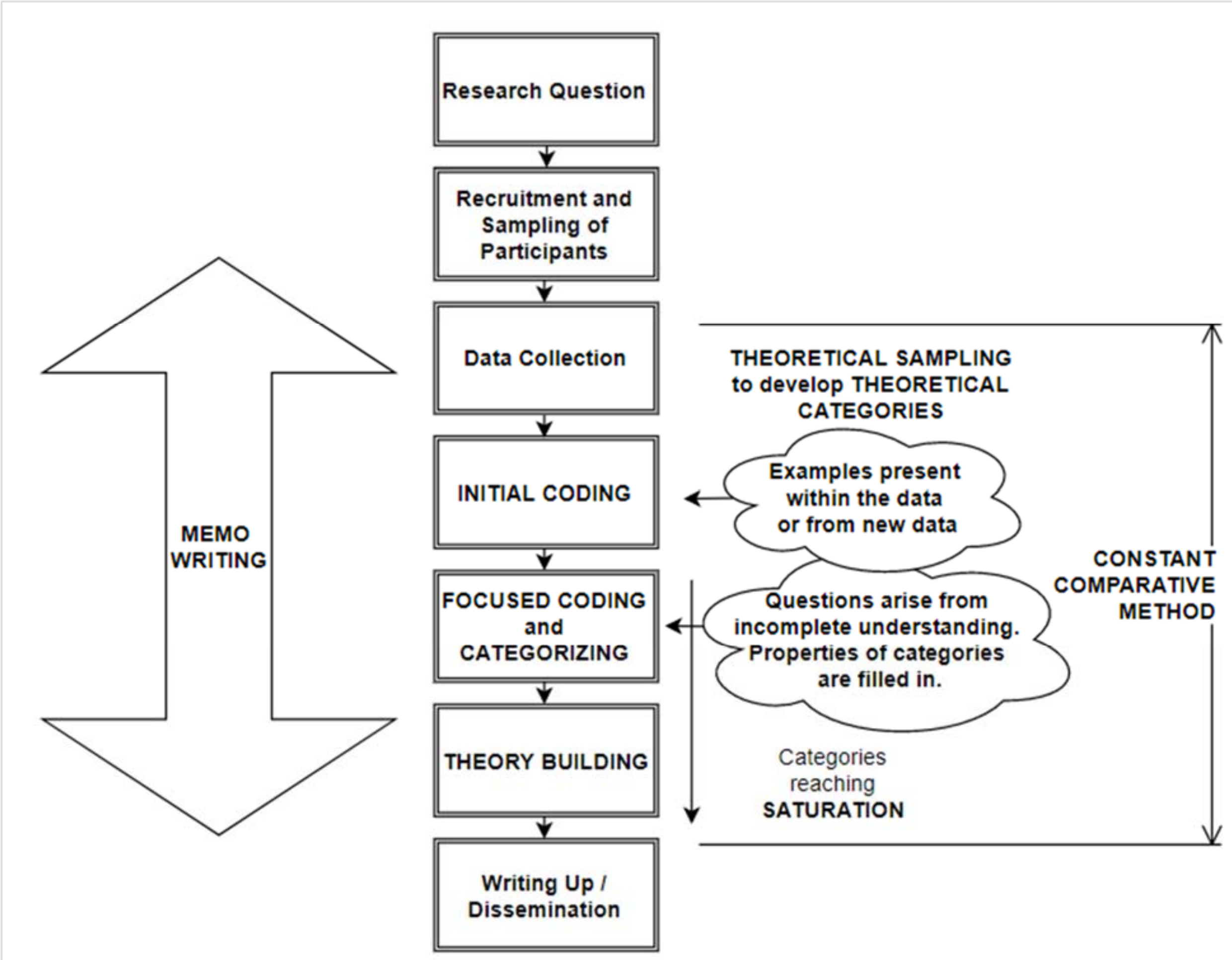

Figure 2. A visual representation of a grounded theory method, as depicted in Charmaz (2014).

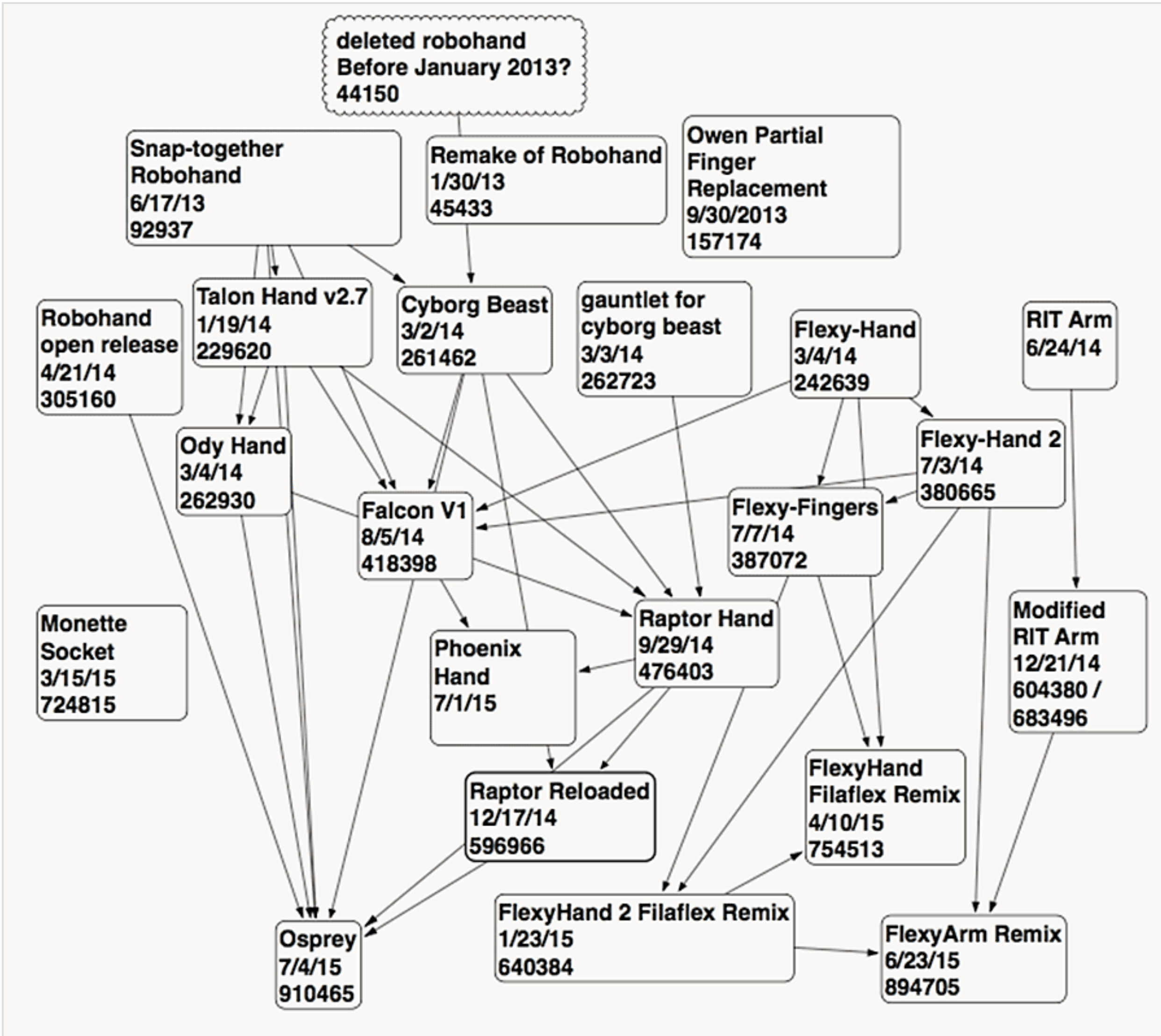

Figure 3. September 2015 diagram of overlapping inheritance between e-NABLE designs, based on reported remixes on Thingiverse and attribution on e-NABLE forums.

Figure 4. A highly customized hand design. Photo: Aaron Brown. Used with permission.

Appendix C Summary of Questionnaire Results

Overview

An online questionnaire (Appendix F) was issued to the e-NABLE Google+ group on February 18, 2015. The primary purpose of the questionnaire was to identify candidates for interviews. Sixty-two community members responded. At the time the questionnaire was posted, there were 4000 members in the e-NABLE Google+ group.

Based on their response to the question “Have you printed, designed, or fabricated a prosthetic device through e-NABLE,” the 62 respondents were divided into 3 groups:

- Successful device fabricators (n = 29, 46.8%), represented in Appendix A as “Fabricator.”
- Aspiring, but not-yet successful, device fabricators (n = 25, 40.3%), represented in Appendix A as “Aspiring.”
- Other community members and volunteers who do not intend to fabricate devices (n = 8, 12.9%), represented in Appendix A as “Non-Fab.”

Simple descriptive statistics (frequencies for variables) were tabulated for questions and appear in Appendix A.

Summary of Findings from Online Questionnaire

From the population of fabricators who were able to print a device, 75.9% work in STEM-related fields, as shown in Table A3. Some examples of STEM-related professions included IT professionals, mechanical engineers, and engineering students. Non-STEM professions included librarians, students of unspecified fields, homemakers and entrepreneurs.

“Helping others” and “personal learning or skill development” are the two most typical benefits that volunteers report, as shown in Table A8. These are also the top two self-reported reasons for producing assistive technology, as shown in Table A9. This is consistent with the model of volunteer motivations, both collective and reflexive, discussed by Hustinx and Lammertyn (2003).

Frequently-reported barriers to fabrication and/or design are: 3D printer issues, difficulty modifying design files, and dealing with different design file standards, as shown in Table A10. In follow-up interviews, participants confirmed these barriers. V02 referred to the "black art of 3D printing," and expressed that he would prefer to concentrate on designs without having to manage 3D printing process that are prone to failure. V07 expressed that he wished e-NABLE would just provide designs that are optimized for printing, because he finds customizing design files for each user to be a difficult process.

Appendix D e-NABLE Volunteer Intake Form

The following is a transliteration of e-NABLE's volunteer intake form as it appeared in January 2016:

"Welcome to e-NABLE!

You have found your way to a magical place where volunteers from all over the world collaborate to make dreams come true. Whether you're here to receive help, offer help, or both… welcome! This form is for both volunteers and potential hand recipients.

e-NABLE is a global community of volunteers developing affordable and accessible assistive technologies such as 3D printed hands. We provide free support and self-help tools so individuals and communities can create devices for themselves.

The standard "e-NABLE Hand" is completely mechanical (no motors!). When you bend your wrist, thin cables anchored to the forearm pull the fingers and thumb inward to grip and hold. When your wrist relaxes, flexible cords pull the fingers back to a resting posture. If the standard design is not appropriate, other designs are available. The "e-NABLE Arm" (for a forearm with elbow, but no wrist) is powered by elbow or shoulder movement and will be available soon. Motorized arms are under development.

You can use this form to give us some basic information, to get on our waiting lists, or to help us development ever-better enabling technologies.

Please use this form to give us some basic information. You will receive a Welcome Email with further instructions shortly after completion of this form. Please save the email for future reference.

Your full name? [open-ended response]

Disclaimer

By accepting any design, plan, component or assembly related to the so called "e-NABLE Hand" and "e-NABLE arm," I understand and agree that any such information or material furnished by any individual associated with the design team is furnished as is without representation or warranties of any kind, express or implied, and is intended to be a gift for the sole purpose of evaluating various design iterations, ideas and modifications. I understand that such improvements are intended to benefit individuals having specific disabilities and are not intended, and shall not be used, for commercial use. I further understand and agree that any individual associated with the e-NABLE organization shall not be liable for any injuries or damages resulting from the use of any of the materials related to the e-NABLE Hand.

I agree to hold or attend no meetings between volunteer and recipient in a private setting. All locations for meetings will be public venues such as public libraries.

I also agree to carefully review the safety guidelines here:

http://enablingthefuture.org/build-a-hand/safety-guidelines/

Before proceeding, do you accept the above disclaimer and agree to review the e-NABLE Safety Guidelines?

- Yes, I have read and accept the above disclaimer
- No

Seeking Help, Offering Help, or Both?

The e-NABLE community is here to assist anyone we can, but we are always looking for new volunteers to help so we can continue to serve more people. If you have interest in helping out, please let us know. You do not need to have a 3D printer or any particular skill-set to participate in the e-NABLE community. There are opportunities for all!

Are you inquiring because you are seeking help? If not, you can skip ahead to the "offering help" section:

- Seeking help
- Offering to help
- Both seeking and offering help

How did you hear about e-NABLE? [open-ended response]

Offering Help

Thank you for offering your assistance! e-NABLE is fueled by the generosity and energy of people like you.

There are many ways to help, and we're not asking for a commitment now. Just give us an indication of which areas might be of interest to you.

The following are brief descriptions of each role in the list below:

BLOGGER - Bloggers are those who maintain a blog that is relevant to the work e-NABLE is doing, or who are interested in writing guest blog posts for the e-NABLE blog.

COMMERCIAL SPONSORSHIP - Any organizations wishing to support the work of e-NABLE, either by contributing hardware, software licenses, or other services.

DESIGNER - Anyone who wants to be involved with the process of designing new and improved models for prosthetic devices and other assistive technologies. 3D modeling skills are a significant benefit, but not required.

DEVELOPER - e-NABLE is a thriving online community with a growing collection of information, models, training materials, etc. Developers are those with programming skills who can assist in building automation, web applications, systems integration, etc.

DOCUMENTATION WRITER - Anyone who enjoys creating documentation can assist here. e-NABLE needs good documentation to help others learn to create these devices for themselves and their communities.

FABRICATOR - Anyone with a 3D printer who's willing to help print parts for others.

MATCHER - Matchers help to connect those who are looking for help with those who are offering help. It is a critically important role for ensuring that everyone coming to e-NABLE receives the assistance they need.

MEDIA PRODUCTION - Anyone interested in producing videos (or photos) for e-NABLE. Videos are especially useful in helping to spread the word and build awareness for this important work.

NON-COMMERCIAL PARTNERSHIP - Anyone interested in establishing a non-commercial partnership with the e-NABLE community (for example, other volunteer organizations with compatible goals).

OST - e-NABLE's OST (Organizational Support Team) assists with all of the behind-the-scenes activities that keep the e-NABLE community running smoothly. This is the administrative and support team for the community.

TEACHER - This one speaks for itself. If you're a teacher, e-NABLE would love to work with you to get more students involved in 3D printing and making prosthetic devices.

TRAINING - Anyone interested in doing training, recording training videos, or developing training materials.

TRANSLATION - Anyone willing to assist with translating e-NABLE documents from English to other languages (or vice versa).

If you would like to support e-NABLE financially, please use our donation form at http://www.enablecommunityfoundation.org/donate/

Please indicate which of the following roles you might be interested in helping out with:

Check all that apply.

- Blogger
- Commercial Sponsorship
- Designer
- Developer
- Documentation Writer
- Fabricator
- Matcher
- Media Production
- Medical Professional
- Non-commercial Partnership
- OST
- Teacher
- Training
- Translation
- Other: [open-ended response]

Communication Preferences

Which of the following languages do you speak?

Please check all that apply.

- Arabic

- Cantonese
- English
- French
- German
- Gujarati
- Hindi
- Italian
- Japanese
- Korean
- Malay/Indonesian
- Mandarin
- Marathi
- Persian
- Polish
- Portuguese
- Punjabi
- Russian
- Spanish
- Thai
- Turkish
- Vietnamese
- Other: [open-ended response]

Please provide your contact information.

All fields below are optional, except for email address and phone number. We use an email-based system to request information and track cases.

We only use the phone for time-sensitive matters.

We DO NOT share this information without permission.

- Your email address:
- Phone number:
- General location (for matching purposes):
- Please indicate your country and a nearby major city.
- Your mailing/shipping address:
- Please list street address, city, state, country and postal code.
- Any additional contact-related information:

If you speak a language other than English, are you able and willing to assist us in translating e-NABLE documents into your language(s)?

- Yes
- Not at this time
- Need more information
- Other:

e-NABLE Google+ Community

e-NABLE members collaborate in a thriving Google+ Community. Everyone is welcome to join and participate, but it's entirely optional.

Please let us know your preference:

Would you be interested in joining the e-NABLE Google+ Community?

- Yes

- Already a member
- Not at this time

Click submit to finish."

Appendix E IRB Approval

R·I·T

Rochester Institute of Technology

RIT Institutional Review Board for the
Protection of Human Subjects in Research
141 Lomb Memorial Drive
Rochester, New York 14623-5604
Phone: 585-475-7673
Fax: 585-475-7990
Email: hmfsrs@rit.edu

Form C
IRB Decision Form

TO: Jeremiah Parry-Hill

FROM: RIT Institutional Review Board

DATE: **January 22, 2015**

RE: Decision of the RIT Institutional Review Board

Project Title – Success Factors in Volunteer Prosthetic Fabrication

The Institutional Review Board (IRB) has taken the following action on your project named above.

☒ Exempt _46.101 (b) (2)_

Now that your project is approved, you may proceed as you described in the Form A.

You are required to submit to the IRB any:

- **Proposed** modifications and wait for approval before implementing them,
- Unanticipated risks, and
- Actual injury to human subjects.

Heather Foti, MPH
Associate Director
Office of Human Subjects Research

Appendix F Online Questionnaire

Study of Volunteer Prosthetic Fabrication

You are invited to participate in a research study of volunteer prosthetic fabrication. We are looking for people who are actively involved in e-NABLE, in order to find patterns in their values and practices. We hope this will shed light on what makes volunteer prosthetic fabrication successful. We also hope to learn about small-scale fabrication in general. We will publish our findings in a journal that allows us to share a copy of the final report freely with the e-NABLE community. The principal researcher is Jeremiah Parry-Hill, a graduate student at the Rochester Institute of Technology (RIT). Dr. Daniel Ashbrook is supervising this study. The decision to join, or not to join, is up to you. We are surveying people aged 18 or older.

WHAT ARE WE ASKING YOU TO DO?

For most people, participation will consist of completing the brief online survey that starts on the next page. Based on your answers, we may ask you to participate in a follow-up interview. If you have questions about the study, contact Jeremiah Parry-Hill or Dr. Daniel Ashbrook. If you have questions or concerns about your experience as a research participant, you may also contact Heather M. Foti, Associate Director of RIT's Human Subjects Research Office (hmfsrs@rit.edu). Do you understand your rights as a research participant, and affirm that you are over age 18?

- Yes, I am ready to continue to the survey, and I am age 18 or older.
- No, I would prefer not to continue, or I am younger than 18. (ends survey)

[section break]

Your country of residence: (text response)

Your professional occupation: (text response)

How many months have you been part of e-NABLE?

[choose one]

- Less than 1 month
- 1-6 months
- 6-12 months
- More than 12 months

In an average week, how many hours do you devote to e-NABLE or related activities?

How did you first learn about e-NABLE? (text response)

What are your role(s) in e-NABLE? [multiple select]

- Fabricator, maker or printer
- Prosthetic designer
- Medical professional
- Software designer or developer
- Community organizer
- Planning or logistics of delivering prosthetics
- Community member
- Spectator or fan
- Other: (text response)

What is your relationship to the recipient(s) of e-NABLE prosthetics? [multiple select]

- You have met recipients through the e-NABLE community
- You know recipients through your professional work
- You know a recipient in your friends or family
- You are a recipient

- You do not know any recipients
- Other: (text response)

Have you printed, designed, or fabricated a prosthetic device through e-NABLE?

- Yes
- No
- Not yet, but I intend to

[section break]

Fabricating or Designing Prosthetics

What were your reasons, or would be your reasons, for fabricating or designing prosthetics? [multiple select]

- To help someone you know
- To use or improve your technical skills
- To express yourself creatively
- To work on a project that benefits others
- To help the e-NABLE community
- Other: (text response)

Please describe your background and experience with fabrication or design in general. (text response)

If you have attempted it, what obstacles or problems have you experienced when fabricating or designing prosthetics? (text response)

Which tools or technologies for fabrication or design do you have access to? These could include 3D printers, software, and so forth. (text response)

If you have access to tools or technologies for fabrication or design, where are they? (multiple select)

- You have them at home
- You use them at work
- You use them at school or at a library
- You use them at a makerspace, hackerspace or tool share
- You use a friend's
- Other: (text response)

[section break]

Concluding questions:

Are there any resources you would need in order to participate in e-NABLE as much as you would like? Please describe them, if any. These could include things like time, equipment, or removal of an obstacle. (text response)

How have you personally benefited from being a part of the e-NABLE online community? (text response)

[section break]

Potential follow-up interview

We may ask some people to take part in interviews about their participation in e-NABLE. We expect these interviews to take 45-60 minutes. Most interviews will be over Skype or Hangouts. For people local to Rochester, NY, interviews could take place in-person. We'll ask people about what they do, what they value, and how they collaborate. We may talk about the specific steps involved in carrying out the work of e-NABLE.

If you would be willing to be contacted for an interview about your experience in e-NABLE, please provide your email address below. If not, leave the email field blank, and select Continue to submit your responses.

Your name (optional): (text response)

Your email address (optional): (text response)

Are you are local to Rochester, NY, and willing to be interviewed face-to-face?

Otherwise, interviews would be conducted through Skype, Hangouts, or text chat, at your preference.

- I am local to Rochester NY, and open to a face-to-face interview.

Optional: Would you like e-NABLE to match your skills to opportunities? If you would like to be referred to e-NABLE's matching service, check the appropriate box below. Your other responses to this survey will be kept confidential.

- I am a potential volunteer willing to be contacted by e-NABLE for matching purposes.
- I am a potential recipient, or guardian of a recipient, willing to be contacted by e-NABLE for matching purposes.

Your responses will be saved when you Submit below:

(Submit)

Appendix G Recruitment Materials

Recruitment notice posted in e-NABLE Google+ group:

Researchers from Rochester Institute of Technology are studying success factors in online communities of volunteer makers. Active makers who are US residents aged 18 or older are invited to apply to participate in this study. Participation involves an online survey, with a potential for a one-hour interview over Google Hangouts or Skype, and the potential for follow-up interviews. Interested participants are invited to complete the survey at: (survey link)

Email invitation to selected participants:

Based on your responses to our online survey, you are invited to participate in an online interview about your experiences as part of the e-NABLE community. If you are interested, please respond with your preferred contact information (Skype or Google Hangouts, and username), and select one of the interview times below in US Eastern time: (list of potential interview times follows). If you are in the Rochester, NY area, please let us know if you would prefer to conduct the interview in-person on the RIT campus. Confidentiality note: We are conducting this invitation over an RIT email account, which is secured by an RIT account password. We will make every effort to protect the information you share during interviews, but we would remind you not to share personal or confidential information over email.

Appendix H Interview Guide

Semi-Directed Interview Questions:

- How did you come to start being involved with e-NABLE?
- How would you characterize your role in e-NABLE?

Using the survey responses as a starting point, go into further detail on:

- Experiences fabricating or designing
- Difficulties encountered
- Workarounds
- Suggestions for improvements (in processes, materials, etc.)
- Say more about your motivations for fabricating assistive technology (if survey response was unclear).
- How often do you find you have to reprint/refabricate a part/send a new part to a recipient?
- Where have you found your greatest joy in all of this?
- How have you benefited from being a part of e-NABLE?

Debrief (end of interview):

- Reiterate what we expect to learn from the study
- Answer any questions the participant has about the study

Appendix I Informed Consent Form

Study of Volunteer Prosthetic Fabrication Context: Informed Consent

You are invited to join a research study of volunteer prosthetic fabrication. We are looking for people who are actively involved in e-NABLE, in order to find patterns in their values and practices. We hope this will shed light on what makes volunteer prosthetic fabrication successful. We also hope to learn about small-scale fabrication in general. We will publish our findings in a venue that allows us to share a copy of the final report freely with the e-NABLE community. The principal researcher is Jeremiah Parry-Hill, a graduate student at the Rochester Institute of Technology (RIT). Dr. Daniel Ashbrook is supervising this study. The decision to join, or not to join, is up to you. Please take whatever time you need to discuss the study with anyone else you wish to. We are surveying people aged 18 or older.

WHAT ARE WE ASKING YOU TO DO?

For most people, participation will consist of completing the brief online survey that starts on the next page. Based on your answers, we may ask you to participate in a follow-up interview.

INTENDED BENEFITS

It is reasonable to expect the following benefits from this research:

- Insight into your own participation in e-NABLE.
- Knowledge about the e-NABLE community's role in connecting prosthetics to people who use them.

We cannot guarantee that you will experience benefits from participating in this study. Others may benefit from the summary of the information you share. You may stop participating at any time you choose. If you choose to stop, you will not lose access to any of the benefits of knowledge described above.

RISKS AND CONFIDENTIALITY

The researchers will take precautions to protect any personal or sensitive information. We recommend you not share information that is proprietary or would otherwise put you at legal risk. We will not use your name in publications that result from this study. We will make every effort to keep your personal information confidential. We will take the following steps to keep information about you confidential:

- We will keep any recordings or notes in a repository accessible only to the researchers. We will encrypt all data.
- We will file any paper notes in a locked drawer in an office accessible only to the researchers.
- Any email communications will be via the researchers' password-protected RIT email accounts. We will never include personal or sensitive information in online communications.
- Any quotes used from interviews will be de-identified by the use of an anonymous identifier.

YOUR RIGHTS AS A RESEARCH PARTICIPANT

Participation in this study is voluntary. You have the right not to take part at all, or to leave the study at any time. Choosing to leave will not result in any penalty or loss of benefits. Choosing to leave will not harm your relationship with the research team or with RIT. If you decide to leave the study, notify Jeremiah Parry-Hill or Daniel Ashbrook. We will cancel all pending appointments and we will not send you further communications.

If you have questions about the study, any problems, unexpected discomforts, or think that something unusual or unexpected is happening, contact Jeremiah Parry-Hill or Dr. Daniel Ashbrook. If you have questions or concerns about your experience as a research participant, you may also contact Heather M. Foti, Associate Director of RIT's Human Subjects Research Office at +1-585-475-7673 or hmfsrs@rit.edu.