Understanding Volunteer AT Fabricators: Opportunities and Challenges in DIY-AT for Others in e-NABLE

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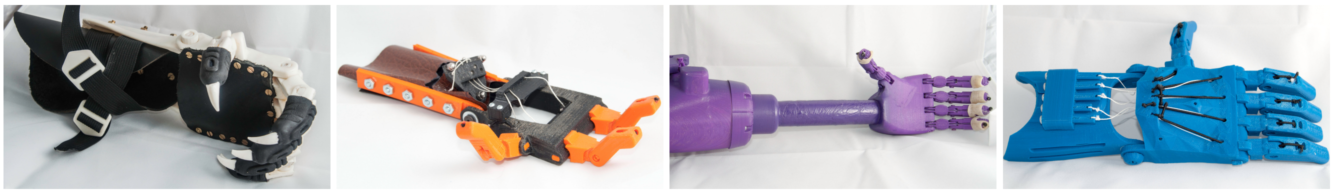

Figure 1. A variety of 3D-printed upper-limb assistive technology devices designed and produced by volunteers in the e-NABLE community. Photos were taken by the fourth author in the e-NABLE lab on RIT's campus.

ABSTRACT
We present the results of a study of e-NABLE, a distributed, collaborative volunteer effort to design and fabricate upper-limb assistive technology devices for limb-different users. Informed by interviews with 14 stakeholders in e-NABLE, including volunteers and clinicians, we discuss differences and synergies among each group with respect to motivations, skills, and perceptions of risks inherent in the project. We found that both groups are motivated to be involved in e-NABLE by the ability to use their skills to help others, and that their skill sets are complementary, but that their different perceptions of risk may result in uneven outcomes or missed expectations for end users. We offer four opportunities for design and technology to enhance the stakeholders' abilities to work together.

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H.5.3. Group and Organization Interfaces: Computer-supported cooperative work; K.4.2. Computers and society: Social issues—Assistive technologies for persons with disabilities.

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

INTRODUCTION
Do-It-Yourself Assistive Technology (DIY-AT) is an emerging phenomenon based on a vision of easily available, inexpensive customized assistive technology [19]. In addition to many of the examples of DIY-AT in the literature [7,16,18], DIY-AT as a form of volunteering has recently appeared: volunteer-based production of assistive devices on behalf of distant strangers. We term this activity "DIY-AT for Others." One prominent example of this activity is the e-NABLE community, the largest extant volunteer community focused on fabricating upper-limb assistive technology. e-NABLE is a loosely knit global community of volunteers—comprising, among others, AT designers, fabricators, coordinators, and recipients—that represents a coordinated effort to make 3D-printed upper limb AT available for free to those in need.

While compelling in principle, the practical realities of the vision of DIY-AT for Others have not been explored in depth, leaving many open and important questions. What are the optimal motivations for sustaining volunteer participation? What are the barriers to volunteer success? What do recipients want from DIY-AT produced from them, what factors increase utility and reduce abandonment? And finally, what are the clinical implications of volunteer-produced AT, and how can volunteers best leverage clinical expertise to increase safety and utility and reduce risk?

We present a study of the e-NABLE community that attempts to answer these questions through interviews with two groups of stakeholders: the fabricators who 3D print, assemble, and deliver the AT, and outside clinicians, such as prosthetists, who have expert knowledge, but often do not participate directly in e-NABLE activities. Our investigation revealed a complex, shifting landscape of motives and ideals that has not been heretofore described. Our findings center on describing the gaps between the stakeholders, adding evidence to prior research on prosthetic device users [2] and the limitations to collaboration between clinicians and makers [15].

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As a social phenomenon, e-NABLE is surprisingly difficult to describe succinctly. It blends a personal fabrication community of practice, a support community for limb difference, a repository of resources for STEM educators, and more. The website of the Enable Community Foundation[7], an organizing body that performs fundraising and outreach activities, describes e-NABLE as "an international network of passionate volunteers using 3D printing technology and STEM education to develop and deploy hyper-affordable prosthetic devices to children and other underserved populations around the world in a safe, sustainable manner." Figure 1 illustrates some examples of the wide variety of upper-limb assistive technology designed and fabricated by e-NABLE volunteers.

The terminology we use in this paper is in keeping with that of the e-NABLE community: we use the term "limb difference" to refer to any reduction in the size of a limb, whether due to trauma, medical amputation or a congenital condition, and "device" or "assistive device" rather than "prosthesis" to refer to the products of the fabrication activities we studied.

In the next section, we briefly introduce e-NABLE in comparison to other volunteer groups providing AT, and then step up a level to explore relevant literature on motivations for volunteerism, the maker movement, and DIY assistive technology production. The section following introduces e-NABLE and the devices it produces. Next, we present our study's goal—answering questions about stakeholder roles, motivations, and difficulties that stakeholders face—along with our interview and analysis methods. Our findings section introduces the three main categories of interviewees—fabricators, designers, and clinicians—and highlights their complementary concerns and needs. Finally, we discuss opportunities for design around topics such as case management, multi-stakeholder co-design, and followup.

BACKGROUND

e-NABLE is an instance of volunteerism, specifically volunteer fabrication. Many volunteer organizations—both partially and entirely online—are dedicated to fabricating assistive devices for people with disabilities (*DIY-AT for Others*). Groups such as the US-based Adaptive Design Association[1] and the UK-based REMAP[2] coordinate volunteers who lend their skills to make assistive technology for people in need on a case-by-case basis. The ramps.org website[3] maintains a list of programs—many volunteer-based—which build free wheelchair ramps for those in need.

More specific to upper-limb difference, similar organizations to e-NABLE include The Victoria Hand Project[4], which focuses on creating sustainable systems to fabricate upper-limb devices in the developing world, and the Helping Hands Foundation[5], a group that provides support and information to families of children with affected upper limbs.

[1] http://www.adaptivedesign.org

[2] http://www.remap.org.uk/volunteering/making-equipment-for-people-with-disabilities

[3] http://www.ramps.org/free-ramps.htm

[4] http://victoriahandproject.com

[5] http://helpinghandsgroup.org

e-NABLE stands out from among these groups because of its exponential growth, the attention it has received in the media, and its relative lack of top down management and clinical expertise. It is a mostly bottom-up volunteer fabrication community in which participants use 3D printing to create affordable prosthetic devices for children and under-served populations around the world. Below, we highlight some open questions about how motivations for volunteerism and making play out in the case of DIY-AT for Others, as well as the definition and meaning of useful assistive technology.

Varied Drives for Volunteerism

Volunteer communities depend on a steady supply of new volunteers, as well as extended participation by seasoned volunteers. For both, it is important to understand what motivates volunteers to participate over time. Motivation to volunteer may be both *collective* (driven by a sense of obligation to the whole group) and *reflective* (driven by a desire for self-realization by fulfilling personal goals) [21]. These motivations are mutually compatible, and vary in their importance for each volunteer. Individual differences in expertise, empathy, reciprocity, obligation, and impact shape both willingness to volunteer and the style of volunteering in different ways for different volunteers [34].

One special category of volunteerism takes place online [10], most prominently in the context of free and open source software (FOSS) development [12, 25, 35]. Similar to other types of volunteering, volunteerism in FOSS projects may be sustained by intrinsic factors such as personal learning [36], to implement some personally desired functionality [31], or reasons such as fun, enjoyment, and the feeling of making a positive contribution [31].

In the case of DIY-AT, studies to date have focused on recipients (e.g., [2]), individuals creating DIY-AT for immediate family members [16], and maker communities encompassing those creating AT for their own use, as a personal challenge, for research purposes, and for universal purposes other than disability [6]. Little is known about the motivations driving volunteers to design and fabricate for others, as is the case for e-NABLE.

Motivations for and Barriers to Making

In contrast to online communities focused on knowledge capture [22], the sharing of code [11], or programming knowledge [26], volunteers creating assistive technology are making a physical artifact. Although creating artifacts by hand is a process as old as human history [5], we are in the midst of what has been called "the new industrial revolution" [1], fueled by inexpensive and easily available technologies such as 3D printers. This "maker" revolution has democratized the act and means of production [33], and is buttressed by a shift in DIY culture from the individual workshop to online web communities [29]. For example, Thingiverse[6] is an online community of amateur makers focused on sharing digital designs for physical objects. Online DIY communities tend to share an ethos of openness and knowledge sharing, where participation is motivated by creative expression and skill acquisition [23].

[6] http://thingiverse.com

While such online communities convey many benefits to makers, the dual physical/virtual nature of DIY practice poses a challenge: sharing a virtual object is much easier than sharing a physical one, but *instantiating* the virtual object as a physical one requires access to technology, material, and skills. This characteristic has given rise to physical makerspaces or hackerspaces [24]: offline spaces where enthusiasts come together to share tools, ideas, and techniques around constructing physical artifacts. In many cases, however, extra support is required for nascent makers. For example, in a study of a repair clinic in California, Rosner and Ames found that even within systems that attempt to empower non-expert users to make functional objects, skilled experts often must be involved [30]. Hudson et al. found that casual makers are deeply dependent on print center operators throughout the process—from bootstrapping their 3D printing workflow, to seeking help and troubleshooting, to verifying their outputs [17].

The creation of DIY-AT—often undertaken via 3D printing—is a small but important component of what occurs in DIY maker communities. DIY makers face difficulties in sustaining their effort due to a lack of basis for assessing the lasting impact of their creations [6], an especially troubling issue in a field where about one in three users abandon the AT they are given [27]. In contrast, non-technical caregivers (e.g., parents providing DIY-AT to children) may question whether they have the ability to produce AT that has a positive impact. These caregivers are concerned about their ability to fabricate assistive technologies, for reasons including social and technical barriers, self-confidence in their own practical ability, hesitation to invest time without the guarantee of a useful outcome, concerns regarding the aesthetics of the devices, and issues related to robustness and safety [16]. Open questions for DIY-AT include whether e-NABLE volunteers have similar motivations and skills to other makers, what barriers they face, and how a community whose stated purpose is AT production navigates the question of AT utility.

The Utility and Safety of DIY Assistive Technology

Abandonment describes the phenomenon of a user ceasing to use an AT device, and is a serious problem for assistive technologies in general [27] and for upper limb prosthetics in particular [4, 28]. Reasons for abandonment may include unattractive appearance of a device, comfort—including device fit and weight—and lack of functional gain, including feeling more functional without a device. DIY assistive technology has advantages in terms of aesthetics, specificity to the task at hand, and customizability. Such benefits can allow fabricated AT to meet new needs, such as addressing social aspects of accessibility including self-expression and identity formation [2, 32].

An advantage particular to 3D-printed assistive technology is its lightweight nature, in terms of both cost and heft, both of which are positively associated with successful outcomes [4, 28]. While 3D-printed devices such as those produced by e-NABLE may not facilitate as wide a range of tasks and activities as conventional prosthetics, they can support psychosocial development, whether that means "standing out" with a unique appendage, or "fitting in" with an anthropomorphic hand [8].

Additionally, DIY-AT for Others has the potential to support a participatory design process, allowing the recipient to help author solutions that meet their needs across both aesthetic and task specific settings (e.g., [13, 20].

One drawback to DIY-AT, however, is that it lacks oversight, a concern that is particularly visible in the context of large and public communities such as e-NABLE. In a recent summit report authored by e-NABLE volunteers, clinicians, and assistive technology researchers, many specific concerns about safety and practicality of 3D-printed substitutes for traditional upper limb prosthetics were raised [15]. However, this report leaves open questions about how e-NABLE volunteers and clinicians navigate these tensions and what the broader e-NABLE community thinks about them.

THE E-NABLE COMMUNITY

e-NABLE is a community of volunteers dedicated to designing, customizing, printing, and delivering 3D-printed assistive technology to those with upper-limb differences. Organized via two web sites (the Enable Community Foundation website[7] and e-NABLE community website[8]), a private Google+ community, a separate web forum, and various other forms of social media, e-NABLE's members exchange open hardware source files, advice, and support around this activity. The main locus of activity is the Google+ community, with over 9,000 members at the time of this writing.

e-NABLE's web sites characterize its mission as, "To enable any child or adult to receive a free or very low cost experimental upper limb prosthetic,"[7] 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 underserved populations around the world."[8]

How e-NABLE is Organized

e-NABLE's volunteers can choose among a wide set of roles. As itemized on the volunteer intake form, these include: fabricating devices, developing devices, blogging, writing documentation, being a regional "matcher" (connecting device fabricators to device recipients), producing media (primarily video and photographs), participating in the organizational team, training others, and translating documents. The volunteer intake form also identifies external roles: commercial sponsors, non-commercial partners, and teachers.

In practice, most volunteers begin as fabricators, the role that is also most prominent on the website, on social media, and in the Google+ community. The fabricator role exists because of the need for the organization to instantiate the software-based AT designs as physical objects that can be distributed to recipients. Fabricators print and assemble e-NABLE devices, which are typically mailed into a distribution center. They may optionally—depending on skill and interest—also interact with recipients, in which case they often personalize (decorate) or customize (change size or even slightly modify) the device and deliver it personally—though not usually *in* person—to the

[7] http://enablecommunityfoundation.org
[8] http://enablingthefuture.org

recipient. To be officially matched with a recipient, fabricators must first pass a test, producing a high quality hand that is vetted by volunteers.

The developer role differs from that of e-NABLE designer/developer, although many participants engage in multiple activities. While the role of developer might be seen as analogous to that of a developer in a FOSS community, in e-NABLE's this role comprises more of an engineering than a programming activity. Developers collaborate on adapting or creating new functionality, evaluating and improving the printability of devices, and devising ways to work better with the many and various 3D model files involved in different projects.

Another common role is 'teacher,' who works with students to fabricate and assemble devices. e-NABLE has an active education initiative, including funding to produce curricular material that is used in scout groups and schools.

It is unclear how often volunteers take on the other roles mentioned on the intake form, which are typically represented in the community by a small number of very dedicated volunteers. Thus, we will describe only the most relevant of these to our study—the "medical professional," meaning prosthetists, orthotists, and physical and occupational therapists. The exact tasks associated with this role are not specified on the community websites. As we discovered in our interviews, medical professionals are not directly involved in fabrication or design, in part due to concerns about incurring legal liability by "treating" recipients.

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 (e.g., Figure 1). Most of these devices share the mechanical property of providing basic grasp assistance and the aesthetic property of appearing—at least to a certain extent—like a human hand. Some advantages of e-NABLE devices over traditional prostheses include personalized aesthetics and lighter weight, both of which are positively associated with successful outcomes [4, 28]. Disadvantages include limited functionality and often the lack of a professionally fit socket (the part of the device that comes into direct contact with the user's body). As a result, e-NABLE's preference is to refer to the hands as *devices* rather than *prostheses*.

The popular perception of an e-NABLE device is that of a prosthesis that changes the recipient's life by virtue of its functionality:

> ...another child who now has an option that she would have never had before.[9]

> ...and can do things that she couldn't do before, like peel potatoes, pick up objects, and catch a ball.[10]

[9] http://enablingthefuture.org/2015/11/24/e-nabling-aruba-%E2%80%A2-a-3d-printed-hand-for-zizi/

[10] http://magazines.scholastic.com/kids-press/news/2016/01/A-Helping-3-D-Hand

Although 3D printing is the primary method of producing devices, many e-NABLE designs include a significant portion of non-printed parts. These can include elastic bands, specialized screws, hook-and-loop fasteners, leather, foam padding, and gel fingertips. Not all of these components are available in all parts of the world.

Because the design files are openly available in various venues, it is difficult for e-NABLE to track the number of devices that have been fabricated for recipients. One community member (V03) estimated at least 800 direct device deliveries to recipients with upper-limb difference had taken place over e-NABLE's lifetime.

STUDY

We conducted a study of e-NABLE volunteers over a period of twenty-two months. The goal of our study was to answer questions about the roles of different stakeholders in the community with respect to motivation for and barriers to participation.

At the inception of the study, the e-NABLE Google+ community had approximately 3,000 registered members, which grew to approximately 9,000 over the duration of our study. To better understand the community, we joined the Google+ community, followed members' posts, and observed e-NABLE's open-invitation video conferencing meetings (including a general "town hall"' meeting, and other open-invitation meetings of research and development groups). We also read through public news articles published about e-NABLE. One of the authors is an active e-NABLE volunteer, and multiple authors have participated in e-NABLE events. Although these forms of participation were motivated by goals separate from this paper, it has helped us to build rapport with a variety of e-NABLE's members including multiple types of stakeholders. Because the e-NABLE Google+ community is not public (requiring a sign-up to access), we do not directly quote from the community, only interviewees and news articles.

Method

Based on our correspondence with the local and online e-NABLE community, we designed a survey to give us a baseline understanding of the skills and motivations of participants in the community and to identify participants for interviews. The survey included questions about self-identified role(s) in e-NABLE, fabrication successes, background and experience with 3D printing, general challenges as an e-NABLE community member, perceived benefits of participation, and demographic information such as time since joining e-NABLE, occupation and age.

In February 2015, we posted an invitation in the Google+ community to complete the online survey, open to all e-NABLE community members. At the time of the invitation, the Google+ community had about 4,000 registered members. We received 63 responses to the preliminary survey. Thirty-nine respondents self-identified as current or aspiring fabricators of assistive devices for e-NABLE.

We used the findings from the survey, along with our review of the literature and study of the online community, to develop a semi-structured interview protocol that could provide deeper insight into the experiences of e-NABLE community members. The interviews began by establishing common ground through questions about how members and volunteers were introduced to the community. We then explored motivations for participation, interactions with various stakeholders, successes and barriers encountered during fabrication, impressions of use and maintenance of a device, and the personal benefits of participating in e-NABLE.

We conducted fourteen interviews. Six interviewees were survey respondents (V01, V02, V05, V07, C02, and C03 in Table 1); the rest were recruited via snowball sampling and direct communication. Our aim was to recruit a representative sample of e-NABLE stakeholders including fabricators, designers and medical professionals (which we refer to as "clinicians"). Our final sample includes a variety of roles within these categories, as highlighted in Table 1. Although our data includes a range of roles and perspectives, an important limitation of our study is a lack of data about recipients and how they use e-NABLE hands: e-NABLE has not released any information on this topic, and recipients are not typically members of the e-NABLE community, making access difficult. While Bennett et al. interviewed five adult e-NABLE recipients [2], and our participants include two volunteers who also use e-NABLE devices, the majority of e-NABLE recipients are minors who are not included in our, or any other public, data.

Nine of the interview sessions took place face-to-face, as permitted by geographic proximity to the researchers. We conducted the remaining five interviews via web conferencing or by telephone. We recorded a total of 14 hours, 10 minutes of interview sessions over the course of the study. The average length of an interview session was 61 minutes. We audio-recorded all of the interviews and transcribed the recordings for analysis.

Data Analysis

We performed analysis continuously throughout the data collection process, using iterative open coding [9]. We began with descriptive coding for each observation, and as our data accumulated, the focus of our analysis continued to evolve. We revised, merged, and broke down codes as the analysis evolved and more data were collected. We also used findings from the analysis to revise the topic of focus in subsequent interviews. In the end, we collated the products of our analysis in the form of codes and notes from the survey, interview, and online community studies. We analyzed this aggregated data using an affinity diagram [3], to find emerging themes, similarities, and differences. During the affinity diagramming process, we grouped a total of 587 quotes into 83 clusters spanning across 11 major intermediate themes. We iteratively refined these intermediate themes into the themes represented in the findings of this paper. Table 1 summarizes the demographics of our participants.

ID	*Gender*	*Age*	*Occupation*	*Role*
V01	F	25	Plastics engineer	Community member
V02	M	71	Ergonomics engineer	Designer, Fabricator
V03	M	62	Researcher	Community member
V04	F	21	Student (engineering)	Designer, Fabricator
V05	F	22	Student (engineering)	Designer, Fabricator
V06	F	42	Student (neurotech.)	Fabricator
V07	M	65	Semi-retired IT	Fabricator
V08	M	34	3D print shop tech.	Fabricator
V09	M	40	CAD technician	Fabricator
V10	M	20	Student (undeclared)	Fabricator
V11	F	43	Logistics coordinator	Community member
C01	M	33	Occupational therapist	Clinician
C02	F	24	Prosthetics student	Clinician in training
C03	F	30	Prosthetist	Clinician

Table 1. Interview participants; a prefix of V indicates "Volunteer" and C indicates "Clinician."

FINDINGS

The findings reported in this section primarily focus on two groups of stakeholders and the overlaps and disconnects between them. The first is *volunteers*: e-NABLE fabricators and designers, as well as other prominent community members involved in facilitating device production. The second is *clinicians*: medical professionals associated with e-NABLE. We describe each group's motivations for participating in e-NABLE, the skills they exercise, the barriers they encounter to participating, and their perceptions of the risks inherent in the project.

Volunteers

Fabricators told us that they participate because they feel that they are able to pursue challenging, meaningful work that impacts someone directly. Although most e-NABLE volunteers do not have personal experience with limb difference, many e-NABLE volunteers are motivated by a one-to-one, personal connection with those they are serving. The ultimate reward for an e-NABLE volunteer's hard work is exhibited in popular videos and press items showing the "unboxing" of hands and the thrilled reactions of the recipients[11]:

> We were able to give [an e-NABLE device] to a little girl, and [the volunteer fabricator] was there to give it to her ... Seeing things like that, and the smile on the faces, it's worth a million dollars. (V11)

In interviews, several volunteers reported "seeing smiling faces" as the ultimate aim of participating in e-NABLE. It is this personal connection of giving a gift that forms one of the cornerstones of volunteering for our interviewees, in line with Hustinx and Lammertyn's reflexive volunteer model [21]

Another reflexive motivation is the satisfaction of technical accomplishment. Similar to Shah's hobbyist-style open-source software developers [31], many e-NABLE volunteers relish the opportunity to develop their technical skills, especially around 3D modeling and printing, and to solve challenging technical problems:

> 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

[11] e.g., https://youtu.be/I3cf49c_WjE

> the problems. And probably it's never been done before. (V02)

Whether pursuing the distinction of solving novel puzzles, or simply attempting to print and assemble multi-part devices, a common thread of technical self-challenge runs through volunteers' motivations to participate in this form of volunteering. The Google+ forums are full of posts about new technological advances or requests for 3D printing or modeling advice.

One of the most common areas of technical knowledge needed amongst e-NABLE volunteers is the ability to manipulate, before printing, the digital designs for the AT devices, both from a fitting standpoint—"*Every individual recipient is different, and everything needs to be adjusted for them.*" (V09)—and for aesthetic customization. To properly adjust the size of the community-provided designs to fit the recipient, for example, a fabricator must clear a number of technical hurdles related to file formats and design software: there is no single standard for 3D CAD file formats or design software used in e-NABLE.

Aside from manipulating 3D files for sizing, many volunteers embrace the challenge of customization, "theming out" (V08) the hands by making aesthetic customizations (e.g., Figure 1):

> I'm actually building [the recipient's] new hand right now ... he loves playing the army games and Call of Duty, so I'm sending him an army-themed, you know, green and brown. (V08)

Although obtaining colored printer filament imposes an unanticipated additional cost for some volunteers, fabricators accepted this as a necessary expense of providing highly personalized devices with a high chance of adoption.

Once files are prepared for printing, volunteers must negotiate the "hocus pocus" (V02) necessary to operate a 3D printer for high-quality results, and then engage in assembling the parts to make a complete, working device:

> It's only $45 worth of materials, to make a hand, but, it's like, you know, 24 hours of babysitting a printer that may fail during that time, and you've got to spend another few hours to assemble it. (V02)

This emphasis on engineering is built into the structure of e-NABLE itself, both culturally and procedurally: a prospective volunteer's first contact may be with one of the e-NABLE websites, which prominently feature links to "Build a Hand." One of the first steps to be undertaken before being matched with a potential recipient is fabricating a test hand to prove technical skill.

As technical skills are emphasized in the implicit value system of e-NABLE, other factors are necessarily less emphasized. As an endeavor that is primarily about engineering, volunteers lack knowledge about assistive technology in general, participatory design, and the medical background necessary to enact true clinical care. Despite these gaps, in designing, customizing, printing, and delivering the AT, e-NABLE volunteers *are* working with recipients, creating custom assistive devices, and aware of possible safety issues.

For example, V01 describes a device customized not only for aesthetic but also practical purposes:

> They wanted to put a MIG [welder] wire feeder [into an e-NABLE arm], so it would feed the wire through the hand, so it would come out the fingertip. (V01)

The example above epitomizes an orientation toward problem solving that sets amateur fabricators apart from clinicians, who have a primary orientation toward risk management. The exercise of problem solving and creativity are areas where e-NABLE volunteers shine: although sometimes stymied by technical issues—file formats, modeling challenges, and 3D printing—they are able to exercise their skills to contribute to the community.

At the same time, volunteers we spoke with are aware that they lack the knowledge possessed by prosthetists and other clinicians:

> I do [have safety concerns], especially because I don't have any training in medicine or devices like that. I'm worried about hyperextension and pinch points, and pressure points. (V04)

Another volunteer described the expectation for recipients to pursue clinical care on their own:

> It's in the paperwork, in the pamphlets that the recipients' families have to sign. That we highly recommend getting involved with an occupational therapist as soon as possible. ... anything different that can add challenges to life, you know, seeing an occupational therapist is very important. So we stress that as important. (V08)

In summary, e-NABLE volunteers are committed to doing social good through the exercise of engineering expertise. While they understand that the involvement of clinical professionals is important, and worry about possible injury to recipients, the acquisition and exercise of technical skills is often the main focus of their activities.

Clinicians

Given their engagement with e-NABLE—which, as an organization is only just beginning to be visible in mainstream clinical venues—the clinicians we interviewed may not be representative of all professional prosthetic device experts. However, the three clinicians we spoke with shared a common, guarded opinion of e-NABLE. They do not represent converts to the movement; if anything, they are an "advance guard," both assessing e-NABLE as a potential threat to their profession while lending their insights in an abstract, informative fashion, to indirectly influence positive patient outcomes.

While volunteers are motivated by the acquisition and exercise of technical skill in an altruistic setting, clinicians are motivated by patient care in their everyday practice. Helping patients manage their greatest perceived loss is a basic tenet of the profession. Because of these differences, clinicians expressed the desire to add their clinical knowledge to help e-NABLE volunteers think beyond just the engineering of devices. This desire manifested in interviews as attempts at end user advocacy:

> Sometimes you have to remind engineers that the end product is for a person. You're not just making a cool thing! What [does the recipient] want it to do? (C02)

Clinicians also reported lending their expertise to e-NABLE by critiquing works-in-progress, rather than becoming involved directly in cases:

> If you want to be safe, you have to look at some of these contraindications, and potential hazards and dangers. . . . So that's kind of where I'm at right now, is to kind of be the crybaby. (C01)

Whereas e-NABLE volunteers take pleasure in enacting aesthetically themed devices for children, such as "superhero hands," clinicians understand that aesthetic customization is nuanced, is personal, and that recipients of all ages benefit from expert counseling around aesthetic considerations:

> You can talk about "How important is how it looks to you?" And that has to come with a disclaimer: It's okay to say that [aesthetics are] important. It's a big deal. And sometimes that takes convincing, because people don't want to sound like they're vain. (C03)

Clinical interactions with a patient, including ongoing needs assessment, are necessarily more complex than simply dispensing a prosthesis. C02 discusses this need in the context of everyday clinical practice:

> . . . every person needs a different one. [For example,] you don't just give [elderly] people the same foot. Some older people like to walk, or they have hills they need to go up, and you actually need pretty good ankles for that. While other people, you might just give them a regular leg because they feel more comfortable. (C02)

In short, whereas e-NABLE volunteers' expertise is engineering-focused, clinicians are trained medical practitioners. In their professional capacities, their motivation is to ensure long-term successful outcomes and safety for their patients. Technical skills are a subset of the range of skills clinicians bring to bear on patient care, alongside patient management. In addition, clinicians' technical skills are more specialized than those of e-NABLE volunteers. One area of deep expertise is fabricating the socket that attaches the prosthesis to the residual limb:

> The prosthetist, knowing anatomy, they're going to pad in all the right places. They know to particularly protect those [bony landmarks]: lateral condyles, medial condyles, the styloid processes on the wrists, if they have a wrist. (C01)

Clinicians know that the idea of a device "working" for a patient goes beyond pure functionality. Device comfort, safety, and relevance to the patient's needs, as proven by use, are primary concerns for the clinician. An uncomfortable experience may lead to potential injuries or device abandonment.

Clinicians also have a variety of nontechnical skills focused on continuing care. They reported that observing patient satisfaction at the moment of device provisioning is nearly guaranteed; true measures of satisfaction must be made over time. To ensure that patients are truly obtaining positive results with their device, clinicians emphasized the importance of followup visits:

> Things are going to change. People are going to encounter things they didn't expect. It's going to be a rare patient that walks out of the office and is wonderfully happy and never comes back for anything and they're still using it all that time. So the only way to make it successful is to have that kind of follow-up. (C03)

Since e-NABLE volunteers do not always possess medical knowledge of how to properly fit a device based on a patient's anatomy or have the ability to provide continuing care after device delivery, clinicians worried that an unsuccessful experience with an e-NABLE device might dissuade recipients from trying other prosthetic devices in the future (including traditional devices):

> If the experience was bad for whatever reason, they don't come back. They don't necessarily see another prosthetist. It's actually more common for them not to use the prosthesis and to have formed this idea that prostheses aren't for them. (C03)

C01 perceived the media stories about e-NABLE device deliveries as playing into the risk of expectation mismatch leading to abandonment:

> If people have a bad experience with an assistive technology device, especially one that's being built up by the media as being miraculous, but then they get the device and something goes wrong, they're disappointed. Then they might not be as likely to try other AT devices in the future. (C01)

For this reason, clinicians tend to be more skeptical of the trial-and-error approach that is often embraced by technologists, and they are less flexible and willing to experiment than the typical e-NABLE volunteer. C03 framed a clinician's aversion to brainstorming as a consequence of an orientation toward risk management:

> So, [if engineers] try to brainstorm something [with us], or you know, proof of concept, discuss things, all of the prosthetists are probably going to respond as if you're going to try to put it on a patient tomorrow. (C03)

Some clinicians hope to contribute to e-NABLE by providing a guideline to educate volunteers on the various device types and when to best introduce them, depending on the individual conditions of the patients:

> What I want to do with the community, eventually, is to set up those standardized tests of hand designs to see how well they work or do not work. (C02)

In summary, as medical professionals, clinicians are focused on patient well-being as their primary concern. Technical skills are a subset of the talents they bring to bear on helping patients address their greatest perceived loss; other professional competencies include expectation management and followup care. The clinicians we interviewed involved themselves in e-NABLE in the hopes of using their knowledge to steer the project toward the areas of most productive positive impact.

Self-fabrication

Two of the e-NABLE volunteers in our interviews are also limb-different e-NABLE device users who actively participate in the device design process, and fabricated their own devices. To maintain their anonymity, we do not attribute their quotes. Because they are not typical e-NABLE device recipients—as adults and highly skilled volunteers—we use their comments as a starting point to try to understand the factors influencing the meanings that recipients attach to e-NABLE and its devices.

These users do not value e-NABLE hands for functional reasons alone. One of the primary functions of prosthetic devices can be for self-expression rather than solely prosthesis, consistent with findings from Bennett et al. [2]: the aesthetic value of such a device is to manage stigma [14] and can influence self-presentation. As one self-fabricating user reported:

> Although the functionality isn't really that great for me, I feel far comfier wearing it than not wearing it when in public. It gives me more confidence.

One self-fabricator described a personal ideal of developing fabrication skills in order to maintain his own body parts without relying on others:

> This is a part of me, it's a work in progress; *I* am a work in progress. It's this idea of seeing yourself as something to work on, something that's worthy of improving, and making better, and maintaining.

In spite of that ideal, though, there is nuance around who is capable of making their own assistive technology. The same skill base that makes a volunteer fabricator successful is required of fabricator-recipients. Not everyone is equipped to operate a 3D printer, or to design printable parts.

Beyond personal fabrication skills, a recipient may not have all of the the clinical knowledge needed for correct device selection and personal outcome management. This professional knowledge can provide perspectives on potential benefits that recipients might not realize through self-experimentation alone.

While we would ideally like to know more about recipients who are not fabricators, this group, particularly the younger recipients who receive the most media attention, is nearly invisible to both e-NABLE itself and the literature. We did not include minors in the scope of this study, nor have any other researchers to date. However, our results are consistent with the only other study including adult e-NABLE recipients [2].

Discussion

Our interviews demonstrate that e-NABLE volunteers and clinicians have much in common. They are both motivated by a desire to use their skills to help people in need. Clinicians by their very nature perform their work in a non-virtual, one-on-one setting. Despite the distributed nature of e-NABLE, volunteers were also highly motivated by the idea of serving a particular individual. These common aspects of motivation, however, do not necessarily translate to shared practices. The number of clinicians involved in e-NABLE is small, and they are inclined to be wary of legal and medical issues; therefore, the clinicians we spoke to aimed to influence e-NABLE community practices, rather than engaging with particular recipients. The volunteers, on the other hand, emphasize the experimental nature of the devices e-NABLE produces, acknowledge their shortcomings in the clinical realm, and encourage recipients to seek out clinicians.

Both groups possess strong sets of skills. The skills of volunteers are engineering-focused: they see the opportunity to solve problems on a large scale through technical know-how, and are willing to expend great effort to prototype and test solutions. The Google+ community forum is full of experiments, technical questions, and stories of success and failure in 3D printing. Clinicians have deep technical skills as well, but are much more tightly focused on prosthetic practice, and may be wary of new and untested proposed technology. They understand sockets, fitting, safety, and long-term use. They also have the non-technical skill set of counseling—helping their patients to identity and articulate their needs, and empowering patients to make decisions that have the highest probability of a successful outcome. These two disparate sets of skills are complementary; the challenge is in how to couple the distributed engineering abilities of volunteers with the localized, in-person techniques of clinicians.

The volunteers acknowledge that there are risks around e-NABLE devices. They worry about factors such as breakage, injury, and improper use, but having less overall experience than clinicians, they—in essence—don't know what they don't know. Clinicians consider the same risks as volunteers, but add factors such as strain on different kinds of tissue and overuse of the unaffected limb. To operationalize this deep knowledge in the context of e-NABLE, however, remains a challenge. The current approach, of trying to impart some of this knowledge into e-NABLE—or, in C01's words, "*To be the 'bad guy,' pointing out the flaws; that we can make these amazing devices even better*"—may meet some success, but may also fail to capture the interest of a sufficiently large group of volunteers.

One of the largest areas of overlap between the e-NABLE volunteer and the e-NABLE-involved clinician is in the lack of concrete information about how the devices are being used. Although there is anecdotal evidence from adult recipients, volunteers' contacts with their own recipients, and stories in the news media, there is no information about the longer-term use of these devices. Both groups are aware of this lack of systematic use information, and both suggest that the solution is to encourage recipient engagement with clinicians.

OPPORTUNITIES FOR DESIGN

In this study, we have described a form of AT provision that has heretofore not been possible: people with affected upper limbs receiving rapidly produced low-cost body-powered prosthetic devices. Our findings identified differences in stakeholder motivations, skills, and perceptions of the risks of 3D-printed prosthetic devices. As with many complex social structures addressing large-scale societal issues, the e-NABLE community presents many opportunities for technological intervention, but at the same time resists quick and easy solutions. In this section, we sketch potential ways in which e-NABLE might sustain itself long-term while positively impacting those it seeks to serve.

We suggest four areas in which attention from researchers might yield fruit: incorporating some clinical expertise into the current framework for bringing device recipients into the e-NABLE system; a unified system to allow for co-design of devices with the involvement of volunteers, clinicians, and recipients; increasing volunteers' non-technical skills in support of improved recipient outcomes; and incorporating sensors for usage patterns into e-NABLE devices in order to inform clinicians and compensate for the lack of post-delivery followup.

Support Systems for Case Management

As we learned in our interviews, there are a wide variety of areas in which clinical expertise is important; however, the number of clinicians involved in e-NABLE is relatively small. Additionally, e-NABLE serves recipient populations who have no easy access to external clinical support. One possibility is to amplify clinical expertise through a "case management" system that encodes knowledge from clinicians about the advantages and disadvantages of devices, as well as encouraging volunteers to follow a more complete process (including follow up, for example). Such a system could also alert volunteers and recipients about situations where clinical input would be most valuable. Such a system would provide volunteers and recipients with a firmer grounding for making informed choices, make them aware of potential risks, and hopefully increase the likelihood of device success.

Platforms for Co-design

Each instance of customized AT for a recipient is an opportunity to design a unique instance of a device. However, design benefits from an ongoing, fluid dialogue, something that is difficult to achieve between fabricators and recipients even when they are co-located. Indeed, although one of the areas of greatest enthusiasm about e-NABLE devices is the ability to create recipient-specific aesthetic customizations, none of our interviewed volunteer fabricators discussed engaging in any sort of iterative dialogue about those customizations with recipients.

The difficulty of designing asynchronously at a distance could be addressed by a platform to engage volunteers and recipients in a co-design process, allowing the recipients to express their desires and preferences, and the volunteers to bring their technical and artistic skills to bear. Any such system, however, would have to be respectful of the mostly underage nature of e-NABLE recipients, as well as the constraints on time and energy that parents operate under.

A second area of opportunity for co-design is between volunteers and clinicians. This opportunity assumes the availability of significant clinical expertise, in contrast to the clinically grounded case management system suggested above. In the case of device co-design, volunteer designers could help with the design of new devices, or task-specific end effector designs intended to be used by multiple people. Clinicians could help to vet these devices and identify risks and safety concerns.

Alternatively, in the case of device provision, as suggested by Hofmann et al. [15], volunteer fabricators could focus on personalization, while clinicians could help to create professionally made sockets. Such a collaborative approach would allow volunteers to maintain the one-on-one relationship with recipients that is so important to their volunteering motivation, while allowing clinicians to have a role in co-creating meaningful solutions for recipients.

Increased Knowledge Sharing Between Stakeholders

The work of e-NABLE requires a wide variety skills from the volunteer. Many parts of our interviews with volunteers reflected the acquisition of skills related to the mysteries of 3D printing, mechanical engineering, and 3D CAD tools. Our clinician interviewees, however, revealed that helping a patient make an informed decision about prosthesis use involves a wide array of non-technical skills that are not apparent in the fabricators we interviewed. As e-NABLE grows, then, there may be an opportunity to use volunteers' enthusiasm for learning to involve them in discussions around clinical matters—understanding the limitations of different mechanical configurations, testing devices to ensure safety, and even helping potential recipients specify prostheses that reflect their individual contexts of use.

Quantified Usage Data

The lack of information about outcomes at the organizational level was also evident at the personal level in our interviews. This situation is not unique to e-NABLE; followup in mainstream prosthetics happens at a lower rate than clinicians wish for. While case management can help with this problem, e-NABLE also has a unique opportunity to collect fine grained, possibly even real-time data about device use. Because e-NABLE custom-manufactures each device, though, there is potential to build in instrumentation to track how and when the devices are used, or trigger follow up when it is most needed. Sensors and radios have been sufficiently miniaturized and optimized for low power that some modern-day smartwatches incorporate accelerometers, magnetometers, gyroscopes, and Bluetooth, and can last for nearly two weeks powered by a small battery. By using similar sensors and power optimizations—or by simply using a smartwatch modified to add a larger battery—researchers could begin tracking how e-NABLE devices are used. Such a data corpus could help volunteers and clinicians find patterns of use (e.g., is the device only used on weekdays?), postulate about how different device characteristics such as weight are a factor in use or non-use, and understand what kinds of questions to ask if and when followup happens.

LIMITATIONS

As time passes, the e-NABLE community continues to grow and evolve. Our research is a snapshot in time of the community, and hence only reflects the attitudes, opinions, skills, motivations, and goals of fourteen community members at a specific moment in time. Some current efforts, for example, attempt to move away from the completely distributed method by which e-NABLE currently operates towards a more-centralized and in-person method of designing and fabricating the devices. In addition, like any study dependent on volunteer participants, our results reflect self-selection bias. In particular, the e-NABLE volunteers we interviewed were people who were very active in e-NABLE and were mostly located in the United States, and our clinician interviewees may hold opinions divergent from professionals who have chosen not to engage with e-NABLE. Future research could benefit from including more voices from outside e-NABLE as well as a wider variety of e-NABLE participants.

CONCLUSION AND FUTURE WORK

In this study, we described e-NABLE, a community that has emerged to provide low-cost and personalized assistive technology to limb-different users. We presented the results of fourteen interviews with different stakeholders in e-NABLE, comprising volunteers and clinicians, and analyzed their overlaps and differences in terms of their motivation to participate in e-NABLE, the skills they bring to the project, and their perceptions of the risks inherent in the project. We found that both groups are motivated to use their skills to help people in need, their skill sets are complementary, and volunteers acknowledge the need for clinician involvement. However, their differing perceptions of the risks of providing experimental devices to limb-different recipients may result in uneven outcomes or missed expectations for end users.

We suggested four opportunities for design: creating a case management system to amplify sparsely available clinical expertise; supporting co-design between recipients and volunteers, or volunteers and clinicians; using volunteers' natural desire for skill acquisition to help them understand and integrate clinical concerns into their work; and augmenting deployed hands with sensors to gain knowledge of how they are used to inform future designs and trigger follow up as needed.

While our work focused on e-NABLE, our results have implications for other volunteer communities whose products may involve risk outside the scope of volunteer knowledge, as well as other communities that involve the production of physical devices for remote recipients.

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