4-2016

Challenges and Opportunities in DFO-AT: A Study of e-NABLE

Jeremiah L. Parry-Hill
Rochester Institute of Technology

Daniel L. Ashbrook
Rochester Institute of Technology

Challenges and Opportunities in DFO-AT: a Study of e-NABLE

Jeremiah Parry-Hill
Rochester Institute of Technology
Rochester, NY, US
jlpetc@rit.edu

Daniel Ashbrook
Rochester Institute of Technology
Rochester, NY, US
daniel.asbrook@rit.edu

ABSTRACT
In this paper, we present the results of a study of the e-NABLE community—a distributed, collaborative volunteer effort to design and fabricate upper-limb assistive technology devices for distant strangers. We position e-NABLE as the prototypical example of "Do-it-yourself For Others Assistive Technology" (DFO-AT) and describe three key findings: how the project does and does not meet the recipient's nuanced needs for functional and social support; how e-NABLE volunteers' motivations compare to those of volunteers for other efforts, including open source software projects; and we explore the challenges inherent in the distance between volunteers and recipients. We also describe opportunities for future research into DFO-AT activities and support tools.

ACM Classification Keywords
H.5.m. Information Interfaces and Presentation (e.g. HCI): Miscellaneous; K.4.2. Computers and society: Social issues – Assistive technologies for persons with disabilities.

Author Keywords
Accessibility; assistive technology; DIY; do it yourself; disability; 3D printing; Digital fabrication; making; volunteer coordination

INTRODUCTION
Do It Yourself Assistive Technology (DIY-AT) has emerged as a response to the unsatisfactory aspects of professionally produced assistive technology (AT), by producing customized assistive technology for an individual user at reduced cost [20].

Figure 1: A 3D-printed upper-limb assistive technology device with extensive aesthetic modifications.

In addition to many of the examples of DIY-AT in the literature [3, 18, 19], 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 "Do-it-yourself For Others Assistive Technology" (DFO-AT). The physical distance between DFO-AT fabricators and recipients creates unique challenges that are not faced by DIY-AT fabricators who produce devices for themselves or for other local individuals.

In this paper, we present a preliminary investigation of an early example of DFO-AT: the e-NABLE community. e-NABLE is a loosely knit global community of volunteers—comprising, among others, AT designers, fabricators, and recipients—that represents a coordinated effort to make 3D-printed upper limb AT available to those in need. We hypothesize that as a DFO-AT effort, e-NABLE is an example of a type of endeavor that will become more common in the near future: networks of volunteers designing, making, and providing technology to distant individuals in need.

Prosthetics provision by request is the only type of DFO-AT endeavor we have observed to-date. This type of DFO-AT community is particularly interesting to study because—as a large-scale network of volunteers—e-NABLE develops semi-standardized designs that, in each unique case, often must be highly customized to an end user. Thus, learning about and describing aspects of this community can make contributions to inform similar future efforts.

We applied constructivist grounded theory [4] to analyze the e-NABLE community and its activities. Our analysis resulted in three key findings—each related to the fact that e-NABLE is a DFO-AT activity wherein the end product is semi-centrally designed by an online community but is customized, physically instantiated and distributed by individual fabricators to remote recipients.

First, we found that despite a community design emphasis on device functionality, the potential needs of e-NABLE device recipients also involve social acceptance and psychosocial development.

Second, we found that as a distributed design activity, e-NABLE shares characteristics with free and open-source software (FOSS) development, particularly as concerns volunteer motivation; however, such motivations may not fully align with the needs of the recipients that e-NABLE serves.

Finally, we found that the at-a-distance aspect of DFO-AT plays out in the relationships between volunteers and recipients in e-NABLE. We provide examples of the opportunities and challenges around selecting a device, customizing it to the user's personal preferences, and sizing and fitting.

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 "prosthetic" to refer to the products of the fabrication activities we studied. We also refer to "cosmesis" throughout the paper, expanding the usual medical sense of mimicking an unaffected limb to include acting as part of an individual's *personal front*—the items worn or carried that affect how they wish to present themselves to the world [16].

BACKGROUND AND RELATED WORK

Volunteering skills for good

Volunteer fabrication projects have a long history. One example is during wartime, where on the so-called "home front" volunteers worked for the benefit of soldiers, assembling care packages, writing letters, knitting socks, and cooking food [17]. In the 1940s, the Red Cross Production Corps, with three divisions in sewing, knitting and surgical dressings, coordinated the amateur wartime production of soft goods for servicemen and clothing for refugees; 3.5 million volunteers contributed to this effort [8]. Other international organizations such as Engineers Without Borders[1] and Habitat for Humanity[2] focus on alleviating poverty through volunteer infrastructure fabrication efforts.

Online design and development communities can be viewed as instances of virtual volunteering, "in which volunteers conduct their activities for agencies and clients over the Internet, in whole or in part" [7]. Free and open source software (FOSS) development activities are often characterized as a form of virtual volunteering [9], and, as we will argue, the e-NABLE DFO-AT community shares some characteristics with virtual volunteering and FOSS efforts. In particular, the motivations of volunteers joining the project and the structure of the volunteer work that takes place can be viewed through the lens of FOSS development.

Many organizations exist—both partially online and entirely online—that are specifically dedicated to assisting people with disabilities. Groups such as the US-based Adaptive Design Association[3] and the UK-based REMAP [4] coordinate volunteers who lend their skills to making assistive technology for disabled people on a case-by-case basis. The ramps.org website[5] maintains a list of programs—many volunteer-based—which build free wheelchair ramps for those in need.

Specific to upper-limb difference, several organizations exist to fabricate AT for those in need. The Victoria Hand Project[6] focuses on creating sustainable systems to fabricate upper-limb prostheses in the developing world. The Helping Hands Foundation[7] is a group that provides support and information to parents, children with affected upper limbs, and their siblings. e-NABLE, the subject of our investigation, is the largest effort of this kind, and focuses on the design, fabrication, and distribution of upper-limb AT to end users.

Assistive Technology Context

Whether DIY-AT or DFO-AT, custom-made assistive technology is compelling for a number of reasons identified by Hook et al. [18]. Individuals with the same category of disability—in this case, a reduction in the size of an arm—have widely varying specifics of the condition. The amount of remaining limb, the motility and strength of the arm, and the physical shape and size all affect how—and which—AT can be used by a person. In addition, an individual's context, including environment and personal outlook and goals can completely change how AT is used: the World Health Organization defines 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." [27]

[1] http://ewb-international.org
[2] http://habitat.org
[3] http://www.adaptivedesign.org
[4] http://www.remap.org.uk/volunteering/making-equipment-for-people-with-disabilities
[5] http://www.ramps.org/free-ramps.htm
[6] http://victoriahandproject.com
[7] http://helpinghandsgroup.org

The prospect of free, volunteer-made devices for children can be especially compelling for parents and caretakers for a variety of reasons. The use of an AT device can support muscular development and gross motor skills [23], but children grow faster than traditional devices can reasonably be obtained at an affordable cost [23]. Obtaining prosthetics through traditional avenues, whether medical or governmental, can be costly, take a long time, and ultimately deliver a device that is not satisfactory [5, 6]. The ability to customize digitally fabricated AT can open up options for an end user that are aligned to their specific circumstances. The rapid production of digitally fabricated AT allows multiple devices to be provided as users' physical and circumstantial needs change over time.

Several recent studies have examined personal fabrication of DIY-AT. Hurst and Tobias identified personal passion, cost, and the ability to customize designs as motivations for users to fabricate DIY-AT [20]. Buehler et al. studied 3D printing in the context of students with special support needs [3]. In a separate study, Buehler et al. examined the potential impact of Thingiverse on DIY-AT practice [2]. Moraiti et al. evaluated a DIY toolkit to enable occupational therapists to adapt soft objects into assistive devices [25].

Hook et al. have studied non-expert stakeholders in the provision of DIY-AT to children, and recommended an increased focus on rapid prototyping and on "development of practical services and communities that support and encourage larger numbers of non-professionals to become involved in making and adapting AT" [18]. In interviews with parents and caretakers of children who would use AT, Hook noted several factors related to their self-perceived ability to fabricate assistive technologies. These factors included 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 [18].

THE e-NABLE PROJECT

In this section, we provide context for our study in the form of an introduction to the e-NABLE community, its goals, and its outputs.

e-NABLE is a global 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[8,9], 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 7,000 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,"[9] 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]

Because the designs are openly available in various venues, it's difficult for e-NABLE to track the number of devices that have been fabricated for recipients. In an interview that we conducted, one community organizer (CO1) estimated at least 800 direct deliveries of a device to a recipient had taken place over e-NABLE's lifetime.

e-NABLE Devices

The devices produced by e-NABLE may be characterized as "basic grasping assists," with most operating by translating a user's wrist or elbow flexion into finger constriction. This is referred to as a "voluntary closed" design; in the resting position, the fingers remain open until the user flexes a wrist or elbow joint to bring the fingers and thumb together.

There is no single "e-NABLE device;" rather, the e-NABLE community uses a constantly evolving array of upper-limb assistive devices. 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.

e-NABLE's fabricators provide a number of types of devices that effect a gross grasping motion, using a cable-pull mechanism to cause the fingers to close. When the recipient has a sufficient remaining palm and range of wrist motion, the devices are actuated by wrist flexion. e-NABLE's fabricators commonly refer to wrist-actuated devices as "hands." The project's designers are also developing arm designs that use the recipient's elbow as a point of actuation, as well as investigating alternative points of actuation, such as shoulder movement.

Although 3D printing is the primary method of producing devices, many 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.

Figures 1 to 3 illustrate some examples of the wide variety of upper-limb assistive technology designed and fabricated by e-NABLE volunteers.

METHODS

While prior research by Hook et al. explored some of the social and technical issues around DIY-AT [18], volunteer fabrication at a distance—"Do-it-yourself For Others AT" (DFO-AT)—introduces a new set of unexplored challenges. To begin to probe some of these challenges, we undertook to study the e-NABLE project. As a large, complex social organization, e-NABLE can be approached from many angles; in this study, we were interested in understanding how e-NABLE is similar to other distributed design and production activities, and how its DFO-AT nature causes it to be different.

Using constructivist grounded theory—an interpretive analytic approach [4]—we collected and analyzed data from multiple

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

(a) Robohand (b) Phoenix Hand (c) Odysseus Hand (d) Modular Training Arm with experimental thumb gripper hand

(e) Cyborg Beast (f) Flexy-Hand (g) Raptor Hand (h) Raptor Reloaded

Figure 2: A variety of hands and arms developed in connection with the e-NABLE community.

sources, including: Google+ community[10] posts, our notes taken during e-NABLE's open-invitation web conferencing meetings (including a general "town hall" meeting, and other open-invitation meetings of research and development groups), an online questionnaire we submitted to the community, and transcripts of interviews with twelve community members.

Throughout data gathering, we refined a set of qualitative codes based on themes in the data. One author was the sole coder in this study. We validated the findings by checking developing interpretations with participants, performing initial coding as we transcribed interview data, and maintaining a reflective journal with analytic memos throughout the study [14]. We generated a set of initial open codes, using general stories in the news media about e-NABLE and DIY prosthetics as input, and applied those codes to the open-ended survey responses in order to identify emerging themes. As online questionnaire responses were returned, we coded the open-ended portions of those responses. We reiteratively wrote analytic memos based on the most salient themes, refined an initial set of open codes into focused codes, and elevated those into categories for analysis. We wrote analytic memos based on interviews, and coded those as well as part of the reiterative coding-writing cycle. We did not attempt to generate theory in this phase of the study [4].

Data Sources

Google+ Community

Although we used material from the e-NABLE Google+ community—including video meetings—in our analysis, the community is technically not public (requiring a sign-up to access); therefore, we do not directly quote from the community, but summarize and paraphrase relevant findings.

[10] http://bitly.com/e-nable

Online Questionnaire

In order to take a wide survey of the backgrounds and experiences of volunteers in e-NABLE, we posted an invitation in the Google+ community to complete an online questionnaire. All e-NABLE community members were invited to respond.

We polled respondents for their occupation, the length of time they had spent in e-NABLE, their self-identified role(s) in e-NABLE, the extent of their success with fabrication, their background and experience with 3D printing, their general challenges as a community member, and their perceived benefits of participation.

We received sixty three responses to the questionnaire. The community had approximately four thousand registered members when the questionnaire was issued, but the number that were active participants—defined as, at minimum, reading community posts—cannot be readily measured. Thirty nine respondents self-identified as current or aspiring fabricators of assistive devices for e-NABLE. Of those, twenty nine reported that they had printed at least one assistive device. Twenty seven of the fabricators worked in a STEM-related occupation (science, technology, engineering or math). Three respondents reported that they were retired, and six were in other professions (librarian, student, or self-employed).

In the text, quotes from questionnaire respondents will be denoted with "QUES" followed by the respondent number.

Interview Participants

In order to gain more insight into the experiences of e-NABLE community members, we requested interviews with several questionnaire respondents. Following the coding and analytic process described by Charmaz [4], we selected participants for later interviews strategically, in order to test and develop emerging analytic categories.

We conducted fifteen interview sessions with twelve individuals. Eleven of the interview sessions took place face-to-face,

ID	Gender	Age	Occupation	Role in e-NABLE
OT1	M	33	Occupational therapist	Test recipient
PL1	F	25	Plastics engineer	Community member
SOP1	F	24	Student (prosthetics)	Lab manager, Fabricator
ENG1	M	71	Retired engineer	Designer, Fabricator
CO1	M	62	Researcher	Community organizer
ST1	F	21	Student (engineering)	Designer, Fabricator
ST2	F	22	Student (engineering)	Designer, Fabricator
ST3	F	42	Student (neurotech.)	Lab manager, Fabricator
FAB1	M	65	Semi-retired IT	Fabricator
FAB2	M	34	3D print shop owner	Fabricator
RCP1	M	40	CAD technician	Recipient, Fabricator
RCP2	M	20	Student (undeclared)	Recipient, Fabricator

Table 1: Interview participants

due to interviewee proximity to our institution. When possible, we conducted the face-to-face interviews in the setting where the participant fabricates assistive technology. Four interviews were conducted over web conferencing or by telephone.

We recorded a total of 11 hours, 42 minutes of interview data over a period of five months. The average length of an interview session was 47 minutes. Table 1 summarizes the demographics of our participants.

FINDINGS

Our study revealed three main findings, influenced by e-NABLE's DFO-AT nature—distributed, volunteer-based, only semi-coordinated, and aimed at the production of individually tailored physical assistive technology.

First, despite popular perception and positive media imagery around e-NABLE hands, the actual experience of recipients correlates with what is generally known in the prosthetic literature—a much more nuanced interplay between psychosocial needs, functionality, limb difference acceptance, and AT abandonment. However, because e-NABLE volunteers are often at both a geographic and cultural remove from the recipients, much of this nuance is not immediately apparent to volunteers.

Second, we found that e-NABLE's organizational and social structure shares some similarities with other volunteering efforts—particularly free and open-source software efforts—but also diverges in important ways. We consider the nature of the involvement of e-NABLE volunteer participants, and reflect particularly on the motivations of e-NABLE device designers and fabricators.

Finally, we uncovered ways that the mediated relationship between the fabricator and the remote recipient presents opportunities and challenges around device selection, aesthetic personalization, and determining the proper size and fit.

RECIPIENT EXPERIENCE

The popular perception of e-NABLE devices, promulgated by both the mass media and e-NABLE itself, is of a prosthetic 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.*[11]

> *. . . and can do things that she couldn't do before, like peel potatoes, pick up objects, and catch a ball.*[12]

> *Children use them for simple tasks like holding water bottles while being able to hold a snack in their other hand at the same time, helping to give them balance by allowing them to use two hands to ride a bike or swing on the swings, holding sports equipment like baseball or cricket bats, catching soccer or footballs etc. and other simple tasks that having two hands is helpful for. Some children have found that swimming with them has been helpful as well.*[13]

The full scope of a recipient's potential need for a device goes beyond the delivery of two-handed capabilities. We found support for the idea that the psychosocial effects of e-NABLE devices are as useful as the functional abilities they afford. This finding agrees with literature on the development of children who use upper-limb assistive technology [12, 28]. Our interviewee RCP2 discussed his experience as a young person with limb difference:

> *Near the end of elementary school. . . I was having such a hard time socially with the kids. I have a few rather unpleasant memories of. . . your standard textbook bullying. I'm sure they would have found other things, but it was like bleeding in a shark tank there.*

Rumsey and Harcourt found that for children with a limb difference, many of the most frequent difficulties centered around social interaction [28]. Because developing children construct their body image based on reactions from individuals in their environments, peer support is an important factor in positive self-perception. In one study, deJong et al. reported that children expressed that negative feelings about their affected limb were the result of negative social interactions such as teasing, staring, and rejection. Conversely, participants in the same study expressed that having peers treat them with respect and admiration allowed them to feel pride and acceptance of their limb difference [12].

RCP2 drew a contrast between how he felt before and after his e-NABLE device:

> *Before I got this [device], every time someone took a picture of me, I had my hands in front of me, either. . . my affected hand was in my pocket, or it was [hidden by] my right hand. You couldn't actually see it. I wasn't even aware I was doing that. . . And now, pictures are always like this: [with the device-wearing hand] front and center.*

This prosthesis-as-cosmesis understanding of e-NABLE helps to explain some of its success: by individually- rather than

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

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

[13] http://enablingthefuture.org/faqs/media-faq/

mass-producing the devices, volunteer fabricators can extensively design the aesthetics of the devices to help a child recipient feel excited about receiving assistive technology.

Not all children, however, want or will continue to want a prosthetic device. Although as an organization e-NABLE has no statistics on device use, it is very common for a recipient of an upper-limb prosthetic to abandon use of the device. In a survey of abandonment literature, Biddiss and Chau found a reported range of rejection from 16% to 66%, with children's rejection rates higher than those of adults [1]. They note in particular that body-powered devices (such as those provided by e-NABLE) have the highest rates of abandonment, due to slow, awkward movements, lack of grip strength, and high energy expenditure needed for operation. Their research also indicates, however, that abandonment should not necessarily be viewed as a negative: they found that 90% of daily activities can be performed one-handed, and that up to 89% of individuals felt they were more functional without a prosthesis.

> *... 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. (RCP1)*

e-NABLE VOLUNTEERING

Our second key finding as relates to e-NABLE's DFO-AT nature is related to volunteer engagement. Considered as an organization, the e-NABLE project has much in common with other distributed engineering efforts such as free and open-source software (FOSS); however, there is a major factor that differentiates e-NABLE from software: the incorporation of fabricated physical assistive technology that is customized for remote end users. In this section, we discuss how this property influences how e-NABLE is organized and how volunteers engage in the effort.

How e-NABLE is Organized

Due to their software-focused nature, FOSS efforts are usually development-focused. Much of the literature on FOSS examines the roles that exist within these activities; for example, Ye and Kishida identified eight roles in FOSS development communities: project leader, core member, active developer, peripheral developer, bug fixer, bug reporter, reader, and passive user [33]. Aside from "passive user," the roles are development-centered.

In contrast, as an activity focused not only on development, but broadly around a social cause, e-NABLE's volunteers encompass a wider set of roles. As itemized on the volunteer intake form, these roles include: blogging, developing, writing documentation, fabricating devices, matching between people looking for help with those who can provide it, producing media (primarily video and photographic), 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.

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

In some senses the "main" role in e-NABLE—most prominent on the website, on social media, and in the Google+ community—is the volunteer device fabricator, a role without an analogue in FOSS. The fabricator role exists because of the need for a way for the organization to instantiate the software-based AT designs into physical objects that can be distributed to recipients.

The fabricator role differs from that of e-NABLE designer/developer: the designer/developer performs original 3D modeling tasks, creating new 3D-printable AT, whereas the fabricator interacts with recipients, customizes and personalizes the 3D models, and prints, assembles, and delivers the device to the end user.

Volunteer motivation

To better understand volunteers' experiences within e-NABLE, we took reference from the volunteering literature, including that focused on FOSS development efforts. In particular, we examined the factors that influence volunteers' decisions to become involved and to continue volunteering with e-NABLE, and focused particularly on the roles of designer and fabricator to understand the interdependencies between those roles.

The reasons that motivate people to volunteer have been well studied. Two factors identified by Hustinx and Lammertyn are a sense of obligation to a community coupled with a desire for a sense of belonging—a *collective* style of volunteering—and a desire for self-realization and fulfilling personal goals—a *reflexive* style [22]. They do not see these as mutually incompatible, but blended together differently for each volunteer.

One style of volunteer participation in e-NABLE is clearly collective. When asked what value he had gotten from participating in e-NABLE, FAB2 replied, "My God. Um... I mean, you know, you get out of it just knowing that you're helping, knowing you're doing good things." QUES54 noted a benefit from "put[ting] my skills to practice helping those who need it, which is a good feeling for me," and QUES24 said, "For the first time in my life I felt that what I learnt at school and liked doing so much could actually change someone's life in such a positive way."

Most of our evidence, however, points to a more reflexive style of volunteering, a finding that agrees with the FOSS literature: Ye and Kishida attribute the sustainability of volunteering in FOSS projects to intrinsic, or reflexive, factors such as learning [33]. Shah identified two types of FOSS developer, both of which we would characterize as working in a reflexive mode: the *need-driven* and the *hobbyist* developer. The need-driven developer starts as a user and becomes a developer in order to implement some personally desired functionality. The hobbyist, in contrast, participates for other reasons such as fun, enjoyment, and the feeling of making a positive contribution [29]. Shah found that the majority of FOSS developers were need-driven.

Figure 3: A customized, 3D-printed upper-limb assistive technology device in use (e-NABLE Talon hand design).

Because e-NABLE's end product is AT, the need-driven volunteer is much less common than in FOSS software projects, simply due to the smaller number of limb-different individuals. However, two of our interviewees—RCP1 and RCP2—are notable exceptions. RCP1 is a professional computer-aided design (CAD) software operator, who was born with a limb difference. After finding e-NABLE, he became a volunteer designer and fabricator. His engagement with the project could be characterized as reciprocity-based need-driven, with his participation as a designer based on wanting others to share his positive experience. Describing his initial involvement, RCP1 said,

> *...I didn't volunteer for the first two candidates, they came to me at first for help...I felt like I couldn't say no...I wanted them to feel the same way I did.*

This motivation agrees with Voida et al.'s study of volunteers, finding in many cases that expertise and empathy influenced volunteering. One of their participants reported volunteering because "I have been there and I know what you are going through" [31].

Our interviewee RCP2 participates in a more conventional needs-driven manner, describing some of the multiple ways in which he has modified the design of his device (illustrated in Figure 3) for his own needs:

> *...I would break fingers constantly. And...the fingers, over time, would get larger. Because I'd break it, we'd make it a bit bigger, and then I'd break it again, make it a bit bigger. It was kind of an evolutionary process.*

> *...at one point, for a while, the cable anchor back here was breaking...things like a heavy fire door, for example, would be enough to rip the cables through...we basically solved that by making it a bit bigger and then doubling the amount of set screws, so there's not as much stress on an individual [screw].*

Whether designers or fabricators, the majority of e-NABLE volunteers, however, can be described more as hobbyists engaging in a reflexive style of volunteering, especially focusing on the technical challenges and rewards of the tasks. For example, FAB2's initial involvement in the community came via a desire for self-challenge:

> *So I was slowly getting used to my [new] printer, and finally getting some decent prints, and really I just wanted to challenge myself to do a multi-part piece. So I went on Thingiverse...[and] I saw the hand design, I thought, "Oh, that looks kind of cool, maybe I'll try to test myself and try to push myself to do this multi-piece part."*

ENG1's engagement is similar:

> *For me, personally, there's some kind of a self-esteem satisfaction related to solving a problem that nobody's ever solved before...being the best at something's one thing, but doing something that has an intrinsic value is more satisfying to me.*

In a 3rd-party interview, one e-NABLE participant noted, "It is incredibly exciting to tweak a design to solve a problem, print it out, try it out until something goes wrong, redesign, reprint[14]."

The challenge-driven nature of the volunteering can be attributed, in part, to the DFO-AT nature of e-NABLE. With the majority of the volunteer work in designing, modifying, and assembling the hand, and with the volunteers and recipients generally remote from one another, the focus on technological accomplishments is naturally foregrounded. This emphasis has consequences, however, in a possible tension between the needs of volunteers for engaging engineering challenges and the needs of recipients for devices that meet their particular needs. SOP1—a orthotics and prosthetics student—commented on one of the impacts of this focus:

> *Also sometimes you have to remind engineers that, about the end product, that it's for a person...a lot of people are like, "Oh yeah, it's for a person!" I'm like, "Yes! You're not just making a cool thing!"*

FABRICATOR/RECIPIENT RELATIONSHIP

Having discussed the experiences of e-NABLE recipients and how volunteers participate within the organization, we now discuss our third key finding: the ways the distance between the fabricator and the recipient impacts device selection, personalization, and sizing and fitting.

In contrast to device designers, many fabricators in e-NABLE contribute by interacting directly with recipients—or, more frequently, with their parents—in order to provide them with the 3D-printed AT. The role played by these volunteers appears on the surface similar to other examples of distributed production [8, 17], but is more complex. Rather than simply acting as a highly distributed factory, the fabricators perform parts of multiple roles: variously as engineers, artists, and prosthetists. The challenge in this relationship, on top of the volunteer work itself, is that the fabricator and recipient are almost always located at a physical distance from one another.

e-NABLE's slogan is "Giving the World a Helping Hand," which serves to illustrate the organization's international focus. Even if a fabricator and recipient are in the same country, they are still frequently not co-located: "I've personally never built

[14] http://blog.solidoodle.com/2014/03/father-and-son-make-prosthetic-device-with-their-solidoodle/

for anybody in my own hometown. I've sent hands to Hawaii, to New Jersey, to Texas…" (FAB2). The lack of direct access to the recipient by the fabricator leads to a number of findings around device selection, custom fitting, and aesthetics.

Device selection

Murray et al. note that there are many dimensions to consider when making an informed match between a recipient and a device:

> *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. [26]*

The e-NABLE websites offer little structured advice to fabricators and recipients to guide the determination of which device would be most appropriate in a given case, concentrating mainly on offering advice for photogrammetric sizing, as well as a wide variety of devices (between the two sites, twenty-two are listed) with general descriptions of each. For information needs beyond the catalog of devices and instructions for obtaining limb measurements, the website suggests seeking advice on a case-by-case basis through the Google+ community or the R&D forums.

Without tools for helping recipients and their families make an informed medical decision, the fabricator who receives a request must accept as a given that the device is necessary in the life of the recipient.

FAB2, a veteran fabricator with experience shipping over 50 devices, described his typical device selection process as follows:

> *…every child is very unique, so we have to look at, of course, whether they have a palm, what their wrist strength is going to be, things like that, so some might be a little better fitted for the Raptor Reloaded, or the regular Raptor might be a better fit. If they're a little older and they want something a little more rugged, we have a couple of other hand designs, the Talon is one.*

However, when prompted for further information on selection, FAB2 admitted:

> *Umm… so [the devices are] pretty plain, they just have a simple grasping motion at this point … A lot of these hands, believe it or not, the kids can do more without them. We hear from the parents, continually, over, just repeatedly, that there's nothing these kids can't do. They can tie their shoes. Some of them can play video games.*

FAB2's understanding of the value and purpose of e-NABLE devices echoes the literature we summarized earlier in Fabricator/Recipient Relationship. He continued:

> *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.*

Personalization

Fabricators often take substantial pride in their aesthetic modifications to standard hand designs, for example readily purchasing different 3D printer material colors to realize "superhero" or "character" hands in various themes. In fact, going beyond designing for child recipients and designing *with* them is a key strength of e-NABLE: participatory AT design case studies by Hussain [21] and De Couvreur et al. [10] indicate that the end user is the best authority on his or her own AT needs, including aesthetic.

In a study in which children were asked to design enabling communication technology, the resultant designs included bright colors, themes from popular TV shows and movies, and ways to personalize the devices [24]. We observed a similar trend in e-NABLE. Our interviewees related that when they ask young recipients about what they want their device to be, they often have appearance-based requests:

> *One kid wanted a Ben-10 hand. Another one wanted a Wolverine hand. (FAB2)*

> *…one boy was 6 years old, the other one was 3 years old, they both wanted Iron Man hands. (FAB1)*

> *We're beginning to be able to show images and examples of the various designs that we have in our library of products to offer. So that the recipient can have some say-so: "I like the looks of this one," or "I want an Iron Man hand," or "I want one that looks more human and delicate. I don't want to look like a robot or have a hook." (ENG1)*

One area in which functionality could be as desirable as appearance is in task-specific devices. Vasluian et al. found that their limb-different focus group participants wanted lightweight, easy-to-don devices that are purpose-built to specific tasks and activities [30], while Wagner and James recommend that a prosthesis should be chosen, not for help with daily activities, but "as a tool to assist with the performance of specific tasks" [32].

e-NABLE's designers have begun to address this aspect of AT. On the community website, there are currently two special-purpose devices, both for musical instruments, and both designed for a particular recipient: one to hold the bow of a viola, and the other to securely grasp a trumpet. A blog post on the same site describes an in-progress BMX bicycle racing adaptation to allow a boy a greater range of movement while securely grasping the handlebars[15].

[15] http://enablingthefuture.org/2015/12/31/e-nabling-the-dream/

Sizing and Fitting

Once a fabricator is connected with a specific recipient, the need exists to customize the device to better fit its intended user. Because the majority of fabricators are geographically distant from their recipients, the process of accurately measuring the recipient's residual limb can be difficult. Zuniga proposed the current standard practice in the e-NABLE community [34]: the recipient provides the fabricator with three top-down photographs from different angles of both the affected and non-affected limbs, with a ruler or tape measure for scale. The fabricator can utilize these photos to calculate specific measurements that they can use to properly size the device.

The recipients' ability to produce good-quality photographs is not guaranteed, however, as their measurements will not be accurate with off-axis (i.e., not directly top-down) images. Some discussion and experimentation has taken place in the Google+ community around using 3D scans of the residual limb for greater accuracy, but this solution presents its own difficulties. 3D scanners are relatively uncommon, expensive, and difficult to use. Scanner output is not guaranteed to be immediately ready for import into a modeling program: often scanned files arrive with holes where the scanner was unable to find the surface, due to lighting and reflectivity issues with the scanned object.

All of the fabricators we interviewed used a photo measurement process, but some used additional methods; for example, FAB2 also described having a parent mail him a tracing of the recipient's affected limb.

Once the fabricator has obtained measurements or a scan of the affected limb, the next challenge is to customize the model. Because every person's residual limb is different, simply scaling the model is not sufficient: the gauntlet (the area of the prosthetic that attaches to the arm) must be modified to fit, and the hand as a whole must be of an appropriate size and weight for the recipient. Recipients who need a prosthetic arm rather than just a hand require more extensive sizing due to the greater variation in length of the human forearm. Fabricators normally utilize 3D modeling software for this, which can be challenging for novices, especially those using free, non-parametric software.

FAB2 related one strategy for managing an iterative sizing process. Rather than printing the entire hand, he printed and mailed only the palm area:

> *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, so that's what I started doing.*

Beyond simple sizing, many fabricators seek advice on ways to adapt design files to fit the unique geometry of their recipient's affected limb. Variations include recipients who have a functional remaining thumb, recipients with nonfunctional remaining fingers, and adult recipients for whom a simple scale-up of child-sized hand designs would not be appropriate or aesthetically appealing.

DISCUSSION

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 prosthetics. We believe this is an early instance of DFO-AT, a form of volunteering that will become more popular as tools for amateur fabrication become more widely available.

Our three key findings—the nuance of the recipient experience, e-NABLE volunteer motivations, and the relationship between volunteers and recipients—suggest future directions for e-NABLE itself, as well as for researchers interested in similar DFO-AT efforts.

Functionality and Appearance

Although engineers may assume that function and the form of a five-fingered hand are the design goals of a system for fabricating upper-limb prosthetics, the literature has shown that the psychosocial developmental needs of young recipients can encompass more than simply enabling bimanual tasks or looking like a conventional human hand. The fabricated AT can be a prop to support the end user's psychosocial development toward self-acceptance [12, 28], and as such, a device that helps the wearer to experience positive social support may be the most powerful AT:

> *... if you can go from being the kid with the weird hand to the kid with the robot hand, you go from being sort of the outcast kid to the kid everyone wants to be friends with. And... that alone is actually enough, right there, not even counting the functionality of it. (RCP2)*

DFO-AT efforts, then, should concentrate on ways for end users to participate more in the provision process, especially as relates to deciding the form and purpose of the fabricated AT. End users' distance from the volunteer fabricator can make such involvement difficult, but presents opportunities to explore systems to surmount the challenge.

Towards DIY-AT

Currently e-NABLE is almost wholly a DFO-AT effort, with very few participants with limb differences also fabricating their own AT devices. Hook et al. [18] found several reasons—many applicable to e-NABLE—that parents of children with disabilities did not engage in DIY-AT: a lack of time to research, develop, and fabricate AT; concerns about the practicality, robustness, safety, and appearance of self-made devices; and lack of skills and confidence to build such devices.

Hook et al.'s findings were related to AT that was largely self-designed and self-implemented; e-NABLE's hybrid model of community-based development with individualized, volunteer-based customization and fabrication alleviates some of these issues. By separating design, production, and recipient roles, e-NABLE allows participants subsets of the qualities identified by Hook et al.: recipients have a reduced time burden, fabricators and designers take on responsibility for appearance and skills for construction, and designers work towards engineering functionality, robustness, and safety.

Despite these positives, the e-NABLE organization currently suffers from overloads, both of people in need of AT and fabricators wanting to make the hardware; on the e-NABLE Community Foundation website, the organizers identify the matching process between qualified fabricators and potential recipients as one of the bottlenecks. One solution might be for recipients to fabricate their own devices; indeed, RCP2 strongly self-identified as a "cyborg" and as such, advocated a position that self-repair of the device—as an extension of self—is a logical outgrowth of self-care:

> *I started to look down on this and not just see a hunk of plastic attached to me, but it's a hand, it's a part of me. It's this idea of seeing yourself as something to work on, something that's worthy of improving, and making better, and upkeeping. Which I think is one of the greatest things that someone could get out of this. Not just the hand, but the idea that . . . you're a work in progress worthy of making better, and that being a central part of your identity.*
>
> *. . . the way that the e-NABLE stuff is set up right now, you've got your recipient and a fabricator. . . whenever someone breaks it, then the fabricator has to come in and fix it, and they have lives. They can't just sit around and wait for parts to break and all that stuff.*
>
> *And I see in the future that this could lead to more people. . . designing their own hands, specializing them to what they do. . . what kind of lifestyle they lead. Do they need a hand that can do the very fine detail stuff? Do they just want something they can wear out to like, hold a glass of wine at dinner parties. Do they need something they can use to move heavy machinery or boxes around, or whatever they need it for.*

Currently, the ability to build, maintain and upgrade a physical device depends on the same skills that e-NABLE volunteers draw upon to make physical devices. As technology improves, though, even the less-skilled end user should be empowered to have input into the process of designing bespoke AT. Opportunities exist to develop systems and tools to support non-expert fabrication of body-worn artifacts. Such systems may tackle the challenges of remote sizing and fitting, as well as ways for end users to consider and have a voice in ways to manage how they wish to be seen with a limb difference. One promising example in the literature is ExoSkin [15], a system using spatial, or projected, augmented reality to allow a user to design and fabricate artistic pieces directly on their own forearm.

Maintaining Motivation

The motivations for volunteers in DFO-AT differ from those of FOSS volunteers, because there are fewer needs-driven volunteers and more hobbyists. Because the needs-driven volunteer is less common—a situation likely to be replicated in other forms of DFO-AT—the majority of volunteers will run the risk of relying on their own values as a proxy for understanding the needs of the remote recipient. DFO-AT support systems should anticipate that some end users may determine that they do not need AT. Rejection or abandonment of AT that is not needed can be perfectly acceptable outcomes, though it may disappoint volunteers. If this happens in large numbers, DFO-AT organizations might consider ways to support and sustain volunteer motivation. Looking beyond direct provision of AT, other ways for hobbyist volunteers to lend their skills may include making the tools to support end-users in the full design of their own AT, or making the tools for collaborative design with remote recipients, so that recipients can be intimately involved in the fabrication that is done on their behalf [11].

Involving Professionals

Multiple studies have illustrated the positive effect of well-matched AT on the psychosocial development of children with a limb difference [12, 28]. Although e-NABLE appears to have the potential to produce AT that is matched to recipients' social and developmental needs, we have not verified whether that is the case. Future researchers, especially in the prosthetic social work fields, may wish to study the impact of volunteer-provided prostheses on recipients, especially as a function of recipient input into the needs that the devices must satisfy.

The knowledge and expertise of trained medical professionals—occupational therapists, prosthetists, and others—should be brought to bear on the design of DFO-AT support systems. One example is heuristics for matching end users with assistive technology. Although models such as the Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST) [13] exist, it is not clear that they are being used to guide the interventions designed by volunteers in e-NABLE. Questionnaires informed by professional expertise are only one example of ways that the wealth of prior health research can be brought to bear on DFO-AT support systems. We encourage future designers and researchers to explore further similar intersections.

Designed Globally, Implemented Locally

Finally, we note that e-NABLE's mission is worldwide. Potential solutions for involving remote recipients of DFO-AT must consider low-tech means of user involvement. For example, 3D scanning is not widely available even in the United States, and is unlikely to be available in less-developed regions. A set of DFO-AT strategies that is ready to meet the needs of all affected users must account for local cultural context and local capabilities, especially when advanced technology is not an option.

ACKNOWLEDGMENTS

The authors gratefully acknowledge the participation of the e-NABLE members who shared their perspectives. This study also benefited from the advice and guidance of Dr. Deborah Gears and Dr. Jonathan Schull. The photograph on page 1 is credited to Aaron Brown.

REFERENCES

1. Elaine A Biddiss and Tom T Chau. 2007. Upper limb prosthesis use and abandonment: A survey of the last 25 years. *Prosthetics and Orthotics International* 31, 3 (Jan. 2007), 236–257.

2. Erin Buehler, Stacy Branham, Abdullah Ali, Jeremy J Chang, Megan Kelly Hofmann, Amy Hurst, and Shaun K. Kane. 2015. Sharing is Caring: Assistive Technology Designs on Thingiverse. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in*

Computing Systems. ACM Press, New York, New York, USA, 525–534.

3. Erin Buehler, Shaun K. Kane, and Amy Hurst. 2014. ABC and 3D: Opportunities and Obstacles to 3D Printing in Special Education Environments. In *Proceedings of the 16th International ACM SIGACCESS Conference on Computers & Accessibility (ASSETS '14)*. ACM, New York, NY, USA, 107–114. DOI: http://dx.doi.org/10.1145/2661334.2661365
4. Kathy Charmaz. 2014. *Constructing grounded theory*. SAGE Publications Ltd., Los Angeles, CA, USA.
5. Jodie Copley and Jenny Ziviani. 2004. Barriers to the use of assistive technology for children with multiple disabilities. *Occupational Therapy International* 11, 4 (Nov. 2004), 229–243.
6. Donna M Cowan and Alan R Turner-Smith. 1999. The User's Perspective on the Provision of Electronic Assistive Technology: Equipped for Life? *The British Journal of Occupational Therapy* 62, 1 (Jan. 1999), 2–6.
7. Jayne Cravens. 2000. Virtual Volunteering: Online Volunteers Providing Assistance to Human Service Agencies. *Journal of Technology in Human Services* 17, 2-3 (Oct. 2000), 119–136.
8. American Red Cross. 2015. World War II Volunteer Special Services. (2015). http://www.redcross.org/about-us/history/red-cross-american-history/WWII/volunteer
9. J L Davidson, U A Mannan, R Naik, and I Dua. 2014. Older Adults and Free/Open Source Software: A Diary Study of First-Time Contributors. In *Proceedings of The International Symposium on Open Collaboration*.
10. Lieven De Couvreur, Walter Dejonghe, Jan Detand, and Richard Goossens. 2013. The Role of Subjective Well-Being in Co-Designing Open-Design Assistive Devices. 7, 3 (2013), 57–70.
11. Lieven De Couvreur and Richard Goossens. 2011. Design for (every)one: co-creation as a bridge between universal design and rehabilitation engineering. *CoDesign* 7, 2 (Sept. 2011), 107–121.
12. Ingrid G M de Jong, Heleen A Reinders-Messelink, Wim G M Janssen, Margriet J Poelma, Iris van Wijk, and Corry K van der Sluis. 2012. Mixed Feelings of Children and Adolescents with Unilateral Congenital Below Elbow Deficiency: An Online Focus Group Study. *PLoS ONE* 7, 6 (June 2012), e37099.
13. Louise Demers, Rhoda Weiss-Lambrou, and Bernadette Ska. 2002. The Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST 2.0): An overview and recent progress. *Technology and Disability* 14 (2002), 101–105.
14. Douglas Ezzy. 2013. *Qualitative analysis*. Routledge.
15. Madeline Gannon, Tovi Grossman, and George Fitzmaurice. 2016. ExoSkin: On-Body Fabrication. In *CHI '16: Proceedings of the 34th Annual ACM Conference on Human Factors in Computing Systems*. To appear.
16. Erving Goffman. 1956. *The Presentation of Self in Everyday Life*.
17. Christopher Michael Head. 2009. *The Armor of Democracy: Volunteerism on the Home Front in World War II California*. Master's thesis. California Polytechnic State University, San Luis Obispo, CA, USA.
18. Jonathan Hook, Sanne Verbaan, Abigail Durrant, Patrick Olivier, and Peter Wright. 2014. A study of the challenges related to DIY assistive technology in the context of children with disabilities. In *DIS '14: Proceedings of the 2014 conference on Designing interactive systems*. New York, New York, USA, 597–606.
19. Amy Hurst and Shaun K. Kane. 2013. Making "making" accessible. In *IDC '13: Proceedings of the 12th International Conference on Interaction Design and Children*. ACM.
20. Amy Hurst and Jasmine Tobias. 2011. Empowering individuals with do-it-yourself assistive technology. In *Proceedings of the 16th International ACM SIGACCESS Conference on Computers & Accessibility*. ACM, 11–18.
21. Sofia Hussain, Elizabeth B N Sanders, and Martin Steinert. 2012. Participatory Design with Marginalized People in Developing Countries: Challenges and Opportunities Experienced in a Field Study in Cambodia. *International Journal of Design* 6, 2 (2012), 91–109.
22. Lesley Hustinx and Frans Lammertyn. 2003. Collective and Reflexive Styles of Volunteering: A Sociological Modernization Perspective. *Voluntas: International Journal of Voluntary and Nonprofit Organizations* 14, 2 (2003), 167–187.
23. David E Krebs, Joan E Edelstein, and Maureen A Thornby. 1991. Prosthetic Management of Children with Limb Deficiencies. *Physical Therapy* 71, 12 (Dec. 1991), 920–934.
24. Janice Light, Rebecca Page, Jennifer Curran, and Laura Pitkin. 2007. Children's ideas for the design of AAC assistive technologies for young children with complex communication needs. *Augmentative and Alternative Communication* 23, 4 (Jan. 2007), 274–287.
25. Argyro Moraiti, Vero Vanden Abeele, Erwin Vanroye, and Luc Geurts. 2015. Empowering Occupational Therapists with a DIY-toolkit for Smart Soft Objects. In *Proceedings of the Ninth International Conference on Tangible, Embedded, and Embodied Interaction (TEI '15)*. ACM, New York, NY, USA, 387–394. DOI: http://dx.doi.org/10.1145/2677199.2680598
26. Christine E Murray, Erin L Kelley-Soderholm, and Thomas L Murray Jr. 2007. Strengths, challenges, and relational processes in families of children with congenital upper limb differences. *Families, Systems, & Health* 25, 3 (Sept. 2007), 276–292.

27. World Health Organization. 2015. Disabilities. (2015). http://who.int/topics/disabilities/en/

28. Nichola Rumsey and Diana Harcourt. 2007. Visible difference amongst children and adolescents: Issues and interventions. *Developmental Neurorehabilitation* 10, 2 (Jan. 2007), 113–123.

29. Sonali K Shah. 2006. Motivation, Governance, and the Viability of Hybrid Forms in Open Source Software Development. *Management science* 52, 7 (July 2006), 1000–1014.

30. Ecaterina Vasluian, Ingrid G M de Jong, Wim G M Janssen, Margriet J Poelma, Iris van Wijk, Heleen A Reinders-Messelink, and Corry K van der Sluis. 2013. Opinions of Youngsters with Congenital Below-Elbow Deficiency, and Those of Their Parents and Professionals Concerning Prosthetic Use and Rehabilitation Treatment. *PLoS ONE* 8, 6 (June 2013), e67101.

31. Amy Voida, Zheng Yao, and Matthias Korn. 2015. (Infra)structures of Volunteering. In *18th ACM Conference on Computer-Supported Collaborative Work*. 1704–1716.

32. Lisa V Wagner, Anita M Bagley, and Michelle A James. 2007. Reasons for Prosthetic Rejection by Children With Unilateral Congenital Transverse Forearm Total Deficiency. *JPO: Journal of Prosthetics and Orthotics* 19, 2 (April 2007), 51–54.

33. Yunwen Ye and K Kishida. 2003. Toward an understanding of the motivation of open source software developers. In *Software Engineering, 2003. Proceedings. 25th International Conference on*. IEEE, 419–429.

34. Jorge Zuniga, Dimitrios Katsavelis, Jean Peck, John Stollberg, Marc Petrykowski, Adam Carson, and Cristina Fernandez. 2015. Cyborg beast: a low-cost 3d-printed prosthetic hand for children with upper-limb differences. *BMC Research Notes* 8, 1 (2015).