Hacking, Switching, Combining: Understanding and Supporting DIY Assistive Technology Design by Blind People

Jaylin Herskovitz
University of Michigan
Ann Arbor, MI, USA
jayhersk@umich.edu

Andi Xu
University of Michigan
Ann Arbor, MI, USA
andixu@umich.edu

Rahaf Alharbi
University of Michigan
Ann Arbor, MI, USA
rmalharb@umich.edu

Anhong Guo
University of Michigan
Ann Arbor, MI, USA
anhong@umich.edu

ABSTRACT

Existing assistive technologies (AT) often fail to support the unique needs of blind and visually impaired (BVI) people. Thus, BVI people have become domain experts in customizing and 'hacking' AT, creatively suiting their needs. We aim to understand this behavior in depth, and how BVI people envision creating future DIY personalized AT. We conducted a multi-part qualitative study with 12 blind participants: an interview on unique uses of AT, a two-week diary study to log use cases, and a scenario-based design session to imagine creating future technologies. We found that participants work to design new AT both implicitly through creative use cases, and explicitly through regular ideation and development. Participants envisioned creating a variety of new technologies, and we summarize expected benefits and concerns of using a DIY technology approach. From our results, we present design considerations for future DIY technology systems to support existing customization and 'hacking' behaviors.

CCS CONCEPTS

• **Human-centered computing → Human computer interaction (HCI)**; **Accessibility**; **Empirical studies in accessibility**; • **Social and professional topics → People with disabilities**.

KEYWORDS

Accessibility, Assistive technology, Do-It-Yourself, Blind, Visual impairment, Interview, Design

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1 INTRODUCTION

Assistive technologies can help blind and visually impaired (BVI) people gain visual access in a variety of situations in their daily lives, including navigating, reading printed text, and identifying objects [2, 20, 89]. Despite their usefulness, there are still a variety of scenarios that artificial intelligence (AI)-based assistive technologies fail to address. This is evidence of a 'long-tail problem' in assistive technology: while AI-based assistive technologies can address simple and common use cases, there are still a vast number of diverse scenarios that AI does not account for. This is in part due to the limitations of existing AI-based assistive technologies; they either cannot be applied yet to scenarios that require human intelligence (e.g., selecting an outfit [35]), or they are not designed well enough for BVI people (e.g., AI models are trained on images from sighted people). However, because AI models are trained for limited types of scenarios, AI-based assistive technologies tend to assume 'universal' needs of BVI people and are thus one-size-fits-all, rather than accounting for unique differences and desires.

In order to address unique needs and improve assistive technology adoption, the concept of Do-It-Yourself (DIY) assistive technologies has emerged. So far, the concept of DIY assistive technologies has largely referred to low-tech physical assistive devices for people with motor impairments, rather than assistive software. Yet, BVI people already engage in customizing and designing their own high-tech assistive technology in order to better suit their needs as early-adopters and domain experts [18], for example, BVI people might create or use add-ons for their screen readers. Thus, applying a DIY approach to high-tech assistive software is a promising path to developing assistive technologies that better meet unique user needs. Current assistive technologies are difficult to 'hack' and alter at the individual level due to both the skill and resources required, and the impossibility of some alterations due to closed software ecosystems. Due to these challenges, new approaches to supporting DIY technology creation are needed to make applying the DIY concept to high-tech assistive technologies for BVI people more feasible. Thus, in this work, we aim to better understand current assistive technology tinkering behaviors so that they can be better supported by future DIY technology creation systems.

In order to reach such a future and understand the expectations and goals of DIY assistive technology, we first aim to answer three prerequisite research questions. **RQ1: Why do BVI people customize existing assistive technology?** Although we know that BVI people work to create and customize assistive technology to their needs [12, 14], we aim to better understand *why* people do this, i.e., the unique needs and scenarios that lead them to desire personalization. **RQ2: How do BVI people customize and 'hack' assistive technologies currently?** By understanding instances of customization workflows, we can better understand desires and design choices in future assistive technology creation. **RQ3: How would BVI people envision creating assistive technology in the future?** Thus, in the future we can better support people in

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DIY-ing the types of assistive technologies that matter to them, leading to more useful assistive technologies.

To answer these questions, we conducted a multi-part qualitative study with 12 blind participants. First, we conducted an interview with participants on their current use of existing assistive technology, focusing on cases where they customized, created, or 'hacked' assistive technology to suit a unique need (RQ1, RQ2). Next, we conducted a two-week diary study where we asked participants to record assistive technology use (RQ1, RQ2). Finally, we conducted a second interview asking participants to envision creating new assistive applications and technologies for their day-to-day tasks, and to provide their thoughts on the concept of DIY assistive technology generally (RQ3).

From our study, we observed that people desired additional personalization in their assistive technologies for a variety of reasons, including due to the variety of unique scenarios encountered (i.e., a long-tail problem), and the lack of options in existing assistive technologies (RQ1). We found that participants regularly engaged in the design of new assistive technologies with a range of strategies, from altering existing assistive technology or applying it to new scenarios, to constant ideation throughout their day-to-day lives, to directly programming new technologies. We highlight this design work, and specifically characterize three common methods for adapting assistive technology to personal needs: hacking, switching, and combining (RQ2). Finally, we discuss participants' self-created assistive technology experiences, ideas, and impressions (RQ3).

Based on our findings, we also discuss design considerations for how existing creation and customization behaviors could be supported by DIY technology creation tools in the future. For example, end-user programming techniques could be a stepping stone towards enabling high-tech DIY assistive technology for BVI people.

Overall, this work has three primary contributions:

(1) An understanding of why and how BVI people engage in assistive technology customization and adaptation, underscoring the need to support new and personalized assistive software solutions.
(2) BVI people's ideas and perspectives on making DIY assistive technology, illustrating the practicalities of using a DIY approach to creating high-tech assistive software.
(3) Design considerations for future DIY assistive software creation tools.

2 RELATED WORK

Here, we review three main categories of related work: (1) the gaps in existing assistive technologies, (2) personalized assistive technology, and (3) DIY assistive technology.

2.1 Existing Assistive Technologies and The Long Tail Problem

While mobile assistive technology at first consisted of expensive and specialized hardware [57], advances in smartphone technology have led to a variety of mobile applications aimed at improving the accessibility of physical tasks. In practice, a wide variety of mobile visual assistance technologies are available commercially [88], ranging in their platform and tasks that they aim to support. These applications are typically powered by either machine intelligence or human intelligence, though research has explored ways to utilize a combination of the two methods in future technologies [65].

For human assistance, applications that allow a blind person to connect to a sighted assistant via video call (often called remote-sighted assistance) have risen in popularity. Aira is a paid, on-demand visual interpreting service [38], and Be My Eyes is a similar volunteer-based service [42]. As these remote-sighted assistance services have broadened in their scope, enabled by two-way video conferencing as compared to static images, so has the set of tasks that they can assist with become more complex [8, 64, 77].

On the machine intelligence side, applications such as Microsoft's Seeing AI [69], Google's Lookout [46], or KNFB Reader developed by the National Federation of the Blind [78] exist. Some mobile assistive technologies are also developed specifically for navigation, for example, Microsoft's Soundscape [70]. Despite advances, fully automated assistive applications are still far from meeting all access needs, thus, people often rely on human assistance for accessibility [22]. While human assistance has the advantage of being flexible to ever-changing needs and contexts, it also has the drawbacks of being costly, not private, and dependent on connectivity and availability of an assistant [3, 9]. Prior work has highlighted the complexity of accessibility needs [43], including the sheer variety of situations encountered [27, 95], the contextual factors [1], and the social factors that influence accessibility needs [29].

This complexity could be understood as a 'long-tail' problem. In statistics, a 'long-tail' distribution refers to a distribution with a large portion of occurrences far from the norm, and in computation can thus describe problems where a small set of common cases are easy to solve, but the vast range of uncommon edge cases make the problem intractable. While the term 'long-tail' has been applied in a variety of different domains, in HCI it largely refers to the large number of unique queries or behaviors in information retrieval [16, 19, 53]. It has also been occasionally applied in accessibility contexts, for example, Billah et al. refer to a long tail of websites and software that are not yet accessible [24], and Pandey et al. refer to a long tail of unique development environments that make it hard to assess accessibility in programming [80].

However, this definition within accessibility could stretch even further to describe the variety of unique contexts and social factors that lead to different assistive technology needs. Characterizing this long tail is important in order to understand how assistive technologies could be improved in the future. In this work, we aim to better understand this so that we can evaluate the potential of personalized and customizable assistive technology.

2.2 Personalizing Technology for Accessibility

Personalizing technology to better meet user needs is a long studied topic within HCI. For example, Chickenfoot is a system enabling users to automate and customize web applications without directly examining the source code [26], and Pagetailor allows users to cutomize website layouts to better fit mobile devices [23].

Similarly, in accessibility research, automatic adaptation and personalization of technology to meet user needs has been considered as a method to reduce the burden of accessibility on users [45, 92], or to better meet specific user needs [93]. Typically, the function of the technology is unchanged, but the input and output mechanisms are adapted [39]. Personalization can be achieved in a variety of ways, including via information stored in user profiles [36] and one-time performance tests [44, 66].

Personalization has also been applied to AI-based mobile assistive technologies by allowing users to input their own data points to be saved and recognized later via teachable object recognizers [28, 56, 94]. While there are privacy concerns to these approaches, [51], they can improve the overall usefulness of mobile assistive technologies by being better suited to users' specific needs. In this work, we hope to further explore how assistive technologies could be customized to better meet a wide variety of unique needs.

2.3 DIY Assistive Technology and Making

Making and Do-It-Yourself (DIY) communities aim to include everyone in creating and designing technologies beyond those formally trained in engineering or computer science fields, and have strong shared values of learning, democratization, and collaboration [60]. Hurst and Tobias first investigated the concept of DIY assistive technology [55], which initially emerged in order to address issues with low adoption of assistive technology (due to discoverability, cost, or lack of an applicable product), changing needs, and customization [50, 55, 79]. In this work, we mainly investigate the potential of DIY assistive software for the latter, that is, custom and unique needs that are not or cannot be met with an off-the-shelf product.

Early case studies of DIY assistive technology tend to highlight a co-design process, where domain experts helped to implement solutions [55]. Research has since worked to make the process of prototyping and making more accessible to all, including non-technical users [40, 54]. Aside from these formal processes, people with disabilities are often continuously involved in the process of making and adapting in order to achieve accessibility [29].

DIY assistive technology can exist on a spectrum from low tech to high tech. This includes solutions ranging from re-purposing existing objects (e.g., a head pointer for painting created from a repurposed face shield [55]), to using advanced fabrication techniques like 3D printing (e.g., a 3D-printed right-angle spoon [54]), to devices that add technological hardware components (e.g., a prototype device for converting images to heat signals [33]), to novel software (e.g., custom open-source software for drawing with eye movements [55]). Most cases of DIY assistive technology in research fall on the low-tech end, due to the resources and experience needed to create higher-complexity devices. Due to these challenges, the process of DIY-ing higher-tech assistive devices in this context typically still involves an expert for guidance [15, 50]. For example, Bennett et al. conducted a series of workshops guiding the assembly of an accessible voltmeter for blind hobbyists [15], identifying that while the desire to create is high, there are still significant barriers to doing so.

Overall, the majority of DIY assistive technology research has focused on physical devices, rather than software. While blind and visually impaired people can benefit from customizable physical devices as well (e.g., money embossers [72] or personalized tactile interfaces [49]), the concept of DIY assistive technology has not yet been fully applied to mobile visual assistance software. In this work, we specifically hope to explore the potential of enabling blind and visually impaired people to independently create assistive software, in order to address their unique needs and desires.

3 METHOD

The goal of our study was to understand why and how BVI people customize existing assistive technology to their needs, and how they might envision creating new personalized assistive technologies for scenarios that they encounter in their daily lives. By understanding blind people's current customizations and desired functionality of assistive technologies, we can better support the unique and 'long tail' needs of BVI users in the future.

We conducted a multi-part qualitative study with three stages: (1) an initial interview, (2) a two-week diary study period, and (3) a second interview. In the first interview, we discussed participants' existing unique uses of assistive technology and conducted a scenario-based design-focused interview to introduce participants to the method. Then, over a two-week diary study participants logged notable scenarios to serve as a basis for the next design session. Finally, in the second interview, we continued the same scenario-based design session, specifically discussing the scenarios that were logged in the diary study, and concluded with a discussion of the idea of DIY-ing assistive technology.

In designing this study, we take inspiration from prior work on facilitating co-design sessions for people with visual impairments. Brewer used a verbal, scenario-based approach to co-design with some success [32]. While co-design work is usually done in a large group setting with multiple participants working together to design or imagine new technology, we chose to conduct one-on-one design-focused interviews with individual participants to focus more on personalized assistive technology solutions, rather than on general solutions for all BVI people.

Our study was approved by our Institutional Review Board (IRB). Participants were compensated $25 per hour for their time and expertise, including the time that they spent composing emails to report scenarios during the diary study. This ranged from 2.5 to 4 hours in total, with an average time of 3.45 hours.

3.1 Research Questions

In this work, we focus on three primary research questions:

- RQ1: Why do BVI people customize existing assistive technology? We aim to better understand the unique needs and scenarios that motivate personalization of assistive technology.
- RQ2: How do BVI people customize and 'hack' assistive technologies currently? We aim to understand how BVI people engage in the technology creation process currently, which can both reveal unique needs that existing assistive technology does not meet, as well as design choices in future assistive technology creation.
- RQ3: How would BVI people envision creating assistive technology in the future? This includes understanding how BVI people would translate their current strategies and needs into future assistive technology designs. Additionally, we also hope to understand what BVI people think about the idea of DIY-ing assistive technology, and how they envision engaging in the creation process in the future.

3.2 Participants

3.2.1 Recruitment. Participants were recruited using prior contacts and snowball sampling, which included participants from an email

ID	Gender	Age	Vision Level	Occupation
P0	Man	32	Some light and color perception, from age 10	Assistive technology researcher
P1	Man	44	Legally blind, lost later in life	Assistive technology researcher
P2	Man	46	Some light perception, from age 5	Accessibility professional
P3	Man	20	Fully blind, from age 5	Computer science university student
P4	Trans/ Non-binary	26	Blind in one eye, some vision in the other, from age 23	Engineering management
P5	Woman	30	Some color perception, from birth	Program manager
P6	Man	59	Fully blind, from birth	Accessibility professional
P7	Man	30	Fully blind, from birth	Programmer
P8	Man	27	Fully blind, from birth	Not employed
P9	Man	29	Fully blind, from age 5	Diversity and inclusion professional
P10	Woman	52	Some light perception, from age 49	Freelance writer
P11	Woman	40	Fully blind, from birth	PhD student
P12	Woman	35	Legally blind, monovisual, cataracts, from birth	Spanish instructor

Table 1: Participant demographics for our study with 12 visually impaired people. Participants self-described their level of vision. All participants used a screen reader to access their devices and read text.

list for blind professionals and writers. Participants were required to be over 18 years old, have some level of visual impairment, and regularly use a screen reader to access their devices. Additionally, we attempted to recruit participants who had varying experiences with technology, but who used a range of assistive technologies in their daily lives, as we wanted to understand the complexities of assistive technology use.

3.2.2 Demographics. Prior to the study, participants filled out a short demographic survey. We recruited 12 participants (four women, 7 men, and one non-binary person), ranging from 20 to 59 years old (see Table 1). Participants had a range of visual abilities: 4 participants with some remaining vision, 2 with some light perception, and 6 with no vision.

We aimed to involve participants with a diverse range of experiences with technology. Of our participants: one was an assistive technology researcher, two were assistive technology specialists, one was a professional programmer. 7 of the 12 participants had prior programming experience, ranging from a participant currently learning to code, to a university student studying programming, to a professional programmer. 4 of the 12 participants had previously programmed some assistive technology.

3.3 Study Protocol

3.3.1 Interview One. We began by asking participants about their use of existing assistive technology (about one hour). Specifically, we asked about unique or memorable uses of assistive technology, life-hacks that they learned over time, or scenarios where technology was not helpful. This served two purposes: first, to understand how participants customized or created new technology workflows. And second, to generate scenarios to serve as a jumping off point for brainstorming.

In the second portion of the interview, we conducted a short scenario-based design-focused interview (about 30 minutes). This served as an introduction to the method, as well as the types of scenarios that participants might log over the diary study. We read participants the list of scenarios that were generated from the first part of the interview, and asked them if any scenario stood out as something that they would like to create a new assistive technology to address. We then worked with them to specify needs and desires for this new technology. For example, we asked participants to verbally describe step by step how they imagined using a new piece of technology, and occasionally prompted participants with feature ideas to determine specifics.

3.3.2 Diary Study. Next, over a period of two weeks, we asked participants to log similar scenarios as they came up in their day-to-day lives. By doing so, we hoped to capture a wider variety of scenarios, as well as more information about the context to serve as grounding in our next design interview. We emailed participants every other weekday with a series of prompts to engage them in this process, and they could respond to these emails as desired. The prompts were the same each time, and asked about unique uses of assistive technology, or gaps in assistive technology that arose in that time period:

(1) Did you use an existing assistive technology in a unique way? What was it?
(2) Did you try to use an assistive technology but it didn't work? What happened?
(3) Did you encounter a scenario that you don't yet have an assistive technology for? What was it?
(4) Did you come up with an idea for a new assistive technology? What would it do?

3.3.3 Interview Two. In the second interview (about one hour), we first asked about the scenarios that participants sent over email, conducting a similar design-focused interview as in the first interview. After this was completed, we then discussed the idea of creating new assistive technologies more generally. We asked participants if this is something they had considered doing before, and what their concerns were. We ended the interview by asking more specific questions about the concept of enabling non-programmers to create assistive technology through a set of provided building blocks or through a shared repository of assistive technologies. We did this in order to elicit specific, concrete ideas about how participants could see themselves creating assistive technologies, rather than discussing the ideas in the abstract. So as not to prime participants, the examples we gave for program building blocks were inspired by things that they had mentioned previously in the interviews (i.e., text recognition, object recognition, spatial audio).

3.4 Data Collection and Analysis

We conducted interviews over Zoom and took audio recordings of each session. Two researchers were present during each interview, with one researcher taking notes and logging scenarios for the second portion of the interview when applicable. We then transcribed the interviews for analysis. These transcribed interviews, plus the emails from participants over the two week diary study, served as our data items.

To analyze this data, two members of the research team performed a qualitative coding following the six phases of thematic analysis that Braun and Clarke described [30]. We used thematic analysis as it best fits our research questions, helping us to understand themes in participants' behaviors and perspectives [31]. Thematic analysis is also used by relevant HCI scholarship with similar interview data [13]. First, the two researchers coded four participants' data synchronously over a Zoom call using an online annotation service. For the remaining participants, the two researches coded each transcript individually, then met to discuss the codes and create a shared annotated version where both were in agreement. During this process, interesting quotes were added to a virtual whiteboard application to group together codes into major themes. We performed weekly reviews as a research team to discuss the findings, and developed a total of 20 higher-level themes.

3.5 Dataset Creation

As part of this analysis, we also synthesized a dataset from the interview transcripts in order to present a deeper understanding of the long-tail problem in assistive technologies for BVI people. In this dataset, we capture diverse scenarios encountered by participants in their daily lives. The dataset consists of individual scenario instances, described with a short summary and participant quotes. For each scenario item, if applicable, we also included the participant's current and desired strategy for accomplishing their goal. A sample of the dataset is shown in Figure 1, and the extended version can be found at https://github.com/HumanAILab/diy-a11y. This dataset could be used in the future to motivate further assistive technology design research.

3.6 Pilot Study

Before recruiting participants, we also conducted one pilot interview with a blind academic researcher. We used this pilot study to refine and finalize the design of our study protocol. Initially, we only planned to conduct the design session in the second interview, but changed this after the pilot study as we realized that the first portion of the interview would generate interesting scenarios and also serve as an introduction to the method. We also made minor changes to the questions asked, for example, we initially planned to ask participants to rate their familiarity with each assistive technology on a Likert scale, but removed this from our final protocol. Finally, we also include some quotes from our pilot study participant where applicable with the ID 'P0.'

4 RESULTS

Here, we present our findings addressing our three research questions. Answering **RQ1**, Sections 4.1 and 4.2 describe the unique needs and scenarios that led participants to desire additional customization in their assistive technology, namely, the variety of unique scenarios encountered and the gaps in current assistive technologies that fail to address those scenarios. Answering **RQ2**, Section 4.3 characterizes *how* participants used three main strategies to adapt their assistive technologies: hacking, switching, and combining. Finally, answering **RQ3**, Sections 4.4 and 4.5 provide participants' ideas and opinions on creating DIY assistive technology in the future.

4.1 Characterizing the Long Tail: Unique Needs Drive Personalization

As our first research question (RQ1), we aimed to better understand why BVI people engage in the process of customizing or 'hacking' existing assistive technologies. Part of this question involves understanding what services (human, machine, and AI-powered) visually impaired people use (summarized in Table 2), and during what scenarios they engage in customization. Here, we aim to emphasize the sheer variety of scenarios that participants encountered in day-to-day life. We identified 65 types of tasks that participants encountered, including 12 types of navigation tasks (e.g., avoiding obstacles, turning, transit, giving directions to others), 13 types of reading tasks (e.g., reading product labels, locating a specific piece of text, understanding memes), and others such as document editing, using inaccessible appliances, and organizing things. More importantly, within these types of tasks, participants' strategies and needs vary in each particular instance. The large variety of unique needs and desires thus is one key driver for customization. We first describe two such instances in depth here (with additional scenarios shown in Figure 1 and provided at https://github.com/HumanAILab/diy-a11y). Then, we describe the variety of scenarios that we observed, in order to illustrate the long-tail problem.

4.1.1 Case 1: Trail Running (P1). P1 described a scenario where they wanted to run on a trail through the forest using the rolling ball tip for their white cane. However, on this specific trail, there were road crossings in numerous places preceded by bollards to block cars from driving on the trail.

As a solution, P1 used the marker feature in Soundscape to mark the location of each road crossing. They did this by first walking along the trail and finding each crossing with their cane, and adding a marker to that location. They were then able to run back along the trail in the opposite direction, and slow down as they approached each crossing. This is a fairly unique use of Soundscape's audio beacons as they are advertised as being markers for points of interests or places to return to; instead, P1 used them to mark known obstacles in their path. Additionally, while Soundscape's beacons may fail at being used in this way in other contexts because of the limitations of GPS location accuracy, that was not an issue in this case. Although the app sometimes notified P1 of the obstacle too early, precision was not as important in this case because they were

Type	Name	Description	Count	Participant IDs
Human assistance	Be My Eyes	Mobile, volunteer-based human assistance	9	P1, P3, P4, P5, P6, P8, P9, P10, P11
	Aira	Mobile and desktop paid human assistance	7	P1, P2, P3, P5, P9, P11, P12
Navigation	Google Maps	Turn-by-turn navigation, traffic, and transit information	11	P1, P2, P3, P5, P6, P7, P8, P9, P10, P11, P12
	Soundscape	3D audio cues for voicing nearby points of interest while navigating	5	P1, P3, P5, P6, P10
	BlindSquare	Accessible turn-by-turn navigation with compass orientation, voiced points of interest, and voice commands.	4	P3, P5, P6, P12
	Good Maps Outdoors	Accessible turn-by-turn navigation with route recording, custom points of interest, and a variety of audio cues.	3	P2, P9, P10
	Compass	Native virtual compass application	2	P3, P12
	Nearby Explorer	Accessible turn-by-turn navigation providing information for orientation including street names and directions	2	P1, P6
AI & Optical Character Recognition (OCR)	Seeing AI	Mobile computer vision for reading text, recognizing color and light, and describing scenes	11	P1, P2, P3, P4, P5, P6, P8, P9, P10, P11, P12
	KNFB Reader	Mobile OCR text-to-speech, text-to-Braille, and text highlighting	5	P2, P5, P6, P10, P12
	Envision AI	Mobile OCR for reading text and products	3	P3, P6, P8
	Tap Tap See	Mobile computer vision for identifying objects in photos	2	P4, P8
Other	Voice assistants	Siri, Alexa, Google Assistant, etc.	5	P1, P2, P4, P6, P8
	Smart appliances	Smart thermostats, smart air-fryers, etc.	3	P1, P2, P6

Table 2: Summary of assistive technologies used by our participants. Includes all technologies mentioned by more than one participant.

able to slow down to a walk and find the specific obstacle with their cane:

> *'I didn't need that much accuracy for those gates, because [Soundscape] has an accuracy around like 50 feet... [This situation] was a little bit different, you know, because those markers were along the path just in front of you. So I didn't actually need to know whether I should take a new angle, like towards something.'* (P1)

P1's ideal solution in this case was to modify Soundscape to be better suited to this task. For example, they wished for an additional setting in the app to set a range for each beacon. They also wished to change the app interface for efficiency. Because this task was repetitive, they wished to automate beacon creation using a Siri command so that they did not have to manually add it each time.

4.1.2 Case 2: Organizing Books (P4). P4 described a set of scenarios where they wished to label objects in their home, one of which was organizing books on a shelf. As P4 became blind recently, they did not have access to tactile labels at the time. As a solution, P4 drew simple labels as a set of shapes on sticky notes. They then placed these on their bookshelf so that each label corresponded with a genre of books (fiction, sci-fi, mystery, etc.). They used Seeing AI to read these labels when needed. This is a DIY approach to creating labels that can be accessed non-visually, created by P4 as they became blind. While P4 described tactile labels as their ideal solution, these DIY labels served an important purpose at the time.

4.1.3 Capturing Scenario Variety. Consistent with prior work, assistive technology use is highly unique to each individual. Although we see common types of tasks (reading, navigation, etc.), the exact scenarios are personalized. Scenarios can vary based on: the specific context and task (how time sensitive, accuracy sensitive, or subjective); the person's background and preferences (their experiences with technology, their level of vision, when and how they lost vision, and how independent they desire to be); and the potential solutions (cost, availability). Based on these needs, people have very different strategies for handling seemingly similar tasks (i.e., what is their first solution, what is their backup plan), and very different ideas for what their ideal solution for a task could look like.

Take for example, the following instances of participants navigating to their room in a hotel. First, participants discussed how they made sure that they got off of the elevators on the correct floor. As P11 described, an elevator may stop unexpectedly if someone calls it from another floor: *"I pressed the number four, but the elevator stopped on the second floor. So someone called from the second floor. But I couldn't know that it was the second floor because [the elevator] didn't have a voice system to tell me that"* (P11). P11 later called Be My Eyes to get information about what floor they were on. However, depending on the environment, further issues may arise. For example, human assistance might not be available: *"I went to [a local hotel] and stayed up there for like, a weekend. And I asked at the front desk when I was checking in, you know, is there someone who can assist me to be able to help me find my room? And she was almost super reluctant to even like, leave her post"* (P12). While remote human assistance may seem better suited to this case, it is also imperfect as described by P12: *"I've been in a hotel, and I've lost signal with Aira. I was trying to have Aira help me find an elevator, and I got on a service elevator. I thought it was never going to get off. When I would stop the elevator, [my service] would go out and I would lose the Aira agent"* (P12). Environmental factors and availability of assistive technology can vary greatly, thus changing a person's requirements in each scenario.

Participants also discussed navigating to the correct room. P11 initially tried using Seeing AI to read the printed room numbers, but

implementing. Human-centered hackathons are events that aim to bridge collaboration between community members and experts to co-create something together [41]. While these collaborations are short term, they demonstrate one potential method for bringing together contributors with different backgrounds.

5.1.3 Creating Visual Access Technologies. Many ideas for future assistive technologies generated by participants in our study involve processing visual information (see Section 4.4). In these cases, the nature of the technology itself can also be an accessibility barrier to creation. While prior work on programming accessibility has largely focused on the accessibility of programming tools and activities such as code navigation and debugging [7, 11, 86], programs where either the input or output is primarily visual remain difficult for blind programmers to create. UI development falls into this category (the output is primarily visual, making testing hard), and prior work has begun to use a variety of strategies to address this, for example, tactile tools for expressing layout [83, 84, 90].

Also in this category are applications in computer vision, which represent a large portion of the imagined future technologies in our study. In these cases, both the input and output are visual, in the form of camera feeds and bounding boxes respectively, among other things. In our study, this was highlighted by P7, a programmer who described not being able to do this type of work effectively. Evidently, this issue goes beyond our work on DIY assistive technologies. Research in the future should focus on how BVI people can create these type of applications, both from an expert and non-expert background. As one potential solution, P7 suggested using synthetic, generated images to test their programs, as then they could more precisely control the input.

5.2 End-User Programming as Future Support for DIY

The concept of DIY assistive technology has not yet been applied to higher-tech assistive software for BVI people. Yet, with new strategies in end-user design, prototyping, and programming, this approach could become more feasible. In this section, we examine how an end-user programming approach to creating DIY assistive software might be used to support existing tinkering behaviors and desires for assistive technology.

5.2.1 Background. Ko et al. define end-user programming as a form of programming done by non-professionals, 'to support some goal in their own domains of expertise' [59]. By creating systems where users can work with graphical interfaces versus writing code directly, programming can become more accessible for non-programmers. For example, Marmite is an end-user programming system for creating 'mashups' that combine the content and functionality of multiple existing sites; it uses graphical dialog boxes to represent operations [96]. As commercial examples, both Shortcuts on iOS [6] and Google Assistant [67] on Android are mobile, end-user programming applications for creating time-saving automations. These applications provide a library of programs that anyone can use, even those who do not want to create their own.

This concept has not yet fully been applied to the space of accessibility to address the gap in creating complex DIY assistive technologies. Thus far, these techniques have largely been applied to improve basic web accessibility by allowing non-programmers to collaboratively improve accessibility [17, 21], rather than to create new assistive technologies.

5.2.2 Supporting Existing Strategies and Ideas with End-User Programming. Given that participants' ideas for future assistive technologies to create vary widely in their scope (ranging from add-ons to existing assistive technology, to new mobile sensing applications, to new hardware, as described in Section 4.4), different approaches to end-user creation are needed. Mobile sensing applications lend themselves particularly well to an end-user programming approach, due to being relatively stand-alone. Here, we present some specific examples for desired future technology that participants proposed during our study, and examine how they could be created with various end-user programming techniques.

Visual Information Filtering. P1 described wanting to filter text to quickly find the expiration date on a package, or the name on a letter. This type of program could use a creation approach similar to Shortcuts or other brief trigger-action programs. For example, a short program could look something like: '`find DATE on BOTTLE`' or '`find MY NAME on PACKAGE`'. As previously mentioned, prior work has aimed to improve the accessibility issues present in block-based programming languages, though further work is needed to improve the accessibility of block-based programming and debugging [71, 75, 76].

Personalized Labeling. Multiple participants mentioned wanting to apply their own, subjective labels to objects, and then later use those labels to either quickly find or sort objects later. For example, P3 wanted to sort their clothes by type, and P5 wanted to fetch spices by the recipe they were used in. Teachable object recognizers are one potential technique that has previously been applied in accessibility contexts [62, 63], but more for the purposes of finding objects rather than creating subjective groupings.

Chaining Services. The 'combining' and 'switching' strategies that participants used to adapt assistive technologies to their needs reflected how participants combine multiple 'channels' available in other applications to create something new. This concept was sometimes extended to ideas for future assistive technologies. For example, P8 envisioned combining a hand tracking service with text recognition to create an application that could guide someone's hand to a button, similar to VizLens [47]. This could be formalized in a creation support tool. Similarly to how iOS's Shortcuts allow users to call functionality from existing applications, chaining together existing services could allow users to create more complex applications.

New Models. Some ideas generated by participants would require training additional models beyond what already exists. For example, P5 expressed wanting Seeing AI to recognize handwriting. A variety of ongoing work has begun to investigate how to allow non-programmers to tweak machine learning models. For example, commercial tools like Google's AutoML [37] or Apple's Create ML [5] allow developers with minimal machine learning experience to fine-tune and customize models. In research, work has aimed to involve people with disabilities in aspects of model training like dataset creation [82], though future work is needed to ensure that these techniques are both fair and functional [48].

5.3 Study Limitations

In our study, we sought out participants who regularly used a variety of assistive technologies so that we could better understand how those technologies are used and altered in day-to-day life. Because of this, while only a minority of our participants were programmers, many of our participants were technically-savvy people who were motivated to regularly engage with new assistive technology. This could be due in part to BVI people (and people with disabilities in general) being 'early-adopters' of new technology [18]. Additionally, because a portion of our participants were originally contacted through an email list for blind professionals and writers, they may lean more technically-savvy then the general population. While we aimed to capture experiences from a diverse range of people in terms of age, gender, level of vision, and occupation, our study's sample may not be representative of the general population of BVI individuals.

Additionally, while our sample size was large enough to demonstrate the range of unique scenarios that people face and their unique solutions, our captured dataset is certainly not an exhaustive list of possible scenarios or solutions. This is due in part to the nature of our investigation of unique needs and use cases. However, our diary study and interview methods also contribute to this factor. We asked participants to log scenarios of interest over a two week period and discussed each one with them, but this method cannot capture (a) scenarios that did not occur over the two week period, or (b) scenarios that participants did not view as significant enough to log. Due to our sample and analysis method, we also did not analyze completely how a person's visual impairment nature and onset affected their desires for assistive technology, beyond the point that it contributes to that individual's unique needs.

Our research focused on high-tech assistive technology due to its prominence in daily use and gaps in prior work on DIY assisive software for BVI people. However, as discussed by some of our participants, low- and no-tech hacks still serve a key role in enabling access for a broad population, and should not be overlooked. Future work can investigate further how these hacks are developed and shared among communities.

This research overlapped with the ongoing COVID-19 pandemic. A few participants shared how this affected their assistive technology use. For example, P4 described using assistive technology less frequently as they stayed at home more. P5 expressed relying on automated assistive technology more during the pandemic, as they were more reluctant to ask random strangers for help. Additionally, some scenarios arise specifically more frequently because of the pandemic, for example, P3 described wanting to create an assistive technology that could help center them in the camera frame when on video calls. In the future, the effects of the pandemic on assistive technology use and independence should be investigated further to better understand and support the unique challenges that arise.

6 CONCLUSION

In this work, we presented an understanding of how BVI people currently engage in assistive technology customization and design, and how they envision DIY-ing assistive technology in the future. Through a multi-part qualitative study, we provided a deeper understanding of the 'long-tail' problem in assistive technologies for BVI people, where current technologies address common use cases but fail to support a wide range of needs and desires encountered in daily life. We identified three strategies (hacking, switching, and combining) that participants used to adapt assistive technologies to their unique needs. Finally, by summarizing participants' ideas and impressions of DIY assistive technology, we provided design considerations for supporting the desire to create in the future.

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