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

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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

ACM Reference Format:
Jaylin Herskovitz, Andi Xu, Rahaf Alharbi, and Anhong Guo. 2023. Hacking, Switching, Combining: Understanding and Supporting DIY Assistive Technology Design by Blind People. In *Proceedings of the 2023 CHI Conference on Human Factors in Computing Systems (CHI '23), April 23–28, 2023, Hamburg, Germany*. ACM, New York, NY, USA, 17 pages. https://doi.org/10.1145/3544548.3581249

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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CHI '23, April 23–28, 2023, Hamburg, Germany
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ACM ISBN 978-1-4503-9421-5/23/04…$15.00
https://doi.org/10.1145/3544548.3581249

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

Key: participant info · setting · task · assistive tech · strategy · ideas · technology · desires

ID	Scenario	Existing Solution	Desired Solution
P1 programmer researcher some vision	Down the road where P1 live is a paved trail through the forest for walking and running. The trail has periodic obstacles. *"There are some gates so that vehicles cannot come to the trail."* outdoor known obstacles unique environment running · white cane accuracy sensitive	P1 used the marker feature in Soundscape. First, P1 walked along the trail and set a marker whenever an obstacle is reached. Then, P1 ran along the trail and had Soundscape alert them when an obstacle is coming so they could slow down and walk. soundscape · location beacons hacking · mark obstacles repeat path	P1 hopes to customize the alert threshold for each marker in Soundscape. *"It would be nice if I could set soundscape alert to me 30 feet before the marker."* It would also be nice to use a Siri command to be able to set markers, instead of having to manually set a marker from within the app. additional settings · re-design controls voice commands · efficiency
P3 programmer student fully blind	Sort their clothes by type, color, etc. *"I tend to sort my clothes into three different piles: indoor, casual, and outdoor."* home · organize subjective · private occurs regularly	Video call a family member to get help. video call · independence	An AI system to help differentiate between a bunch of different clothes (e.g. sort based on color or type): *"I think it's possible for AI to be able to differentiate between a bunch of different clothes if you're training for a little bit."* Someone could first display the clothes to the system, and then can add their own labels to the item. Later, they could scan an item, and the system could output the label associated with it. new mobile app · custom object labels teachable object recognizers
P10 fully blind	Use an electric piano. It has a digital screen, and many buttons that have multiple icons. The buttons do different things depending on if they are pushed once or twice. use appliance learn new interface multi-step	Play with the keyboard and try to remember with trial and error and notes on their phone. Seeing AI can read some text on the screen, but it can't tell you which setting is selected. trial and error · notes Seeing AI	The keyboard could make different sounds when different buttons are clicked. If Seeing AI could add a channel that recognize highlighted text, that could be a solution. recognize formatted text audio hardware
P11 fully blind student	Using an elevator with strangers, it's not easy to know what floor the door is opening on. indoor · hotel indoor navigation time sensitive independence	First used Seeing AI, but failed to find the floor number. Then they switched to Be My Eyes to ask the volunteers to search for the numbers and read the numbers on the door. switching · Seeing AI Be My Eyes multi-step	An indoor GPS system that could tell what floor of a building you're on for easier elevator use. Or, an app specifically for use in elevators, to *"announce the floor numbers or detect what floor you are on when there is not the vocal synthesizes there on the elevator."* new mobile app · audio
P11 fully blind student	Do an at-home Covid test. Had trouble reading instruction manual and seeing the results. reading · private accuracy sensitive independence	Would not use Be My Eyes, because it is health data and too sensitive to share. Asked friend or families for help instead. friends and family privacy	The test kit could have audio that beeps differently to show results. There could also be a QR code on the package directing the user to an online instruction manual. audio hardware · QR code
P12 fully blind	Find a specific room in a hotel. First need to get into the elevator, then find the room. The people at the front desk were reluctant to help. indoor · hotel indoor navigation multi-step independence	Used AIRA, but it's difficult to listen to communicate via phone while trying to walk or manage other things around them. The environment can be loud and distracting. Using AIRA would lower their own navigation skills. Also, they would lose signal and be disconnected with agents when in the elevator. connection issue Aira · focus	An ideal system would combine BlindSquare and AIRA and would use voice announcement or audio notification. The system would announce information like "the elevator is on the right," keeping quiet for rest of the time. Buildings can also have new infrastructure that cooperates with BlindSquare to provide more information like floor plans. new mobile app · audio filtered output

Figure 1: Table of example scenarios mentioned by participants. We highlight relevant codes associated with each scenario. We aim to showcase a diverse set of scenarios here in different domains where participants used different strategies.

the numbers were not where they expected: *"The problem was that the number was really high up, and I didn't really know how high they were so I couldn't detect them. And so then I had to use Be My Eyes"* (P11). However, once they knew where the numbers were printed, they were able to use Seeing AI each time they returned to their room: *"Once I discovered where the number was, I also used [Seeing AI] the next time"* (P11). In this way, P11 used human assistance once to shape their mental model of the environment, and then was able to rely on their preferred method of an AI-based assistive technology to confirm their location. P12 imagined a different solution though, saying that if there was something that worked like BlindSquare [25] in the hotel, *"I could do it by myself, I wouldn't need anybody's assistance, I wouldn't need to call Aira... I could get a general sense [of the environment using BlindSquare]. And then maybe call Aira just to confirm"* (P12). Despite performing similar tasks, different participants had different preferences and strategies that they would prefer to follow, further illustrating the 'long-tail' of needs and customizations.

4.2 Gaps in Current Assistive Technology

While the uniqueness of user needs can account for much of the need for customization, here we aim to highlight a few reasons for customization more specifically (RQ1).

4.2.1 Existing Customization Options Do Not Support Long Tail Needs. Existing customizations are limited by the options that the technology provides. It is common for users to adjust properties of their screen readers, for example, the reading speed, pitch, and shortcuts, as P2 describes: *"I have made customizations such as increasing the speed of the screen reader, or increasing the pitch whenever it encounters caps or things of that nature"* (P2). With desktop screen readers, users can download add-ons, create quick jump bookmarks (P3), and even program their own macros in order to customize behavior (P7). However, when it comes to other assistive technologies, the options for customization are limited. P0 (pilot study participant) noted this issue:

> *"When we think about customization, the programmability is limited to screen readers, so like JAWS and NVDA, they have their own scripts. But I really liked this idea that you could expand this programmability or scriptability to a mobile situation."* (P0)

Many mobile assistive applications have settings to customize the speech output (e.g., voice, reading speed) or other audio cues, and in some cases, allow users to set their own Siri shortcut commands to quickly access functionality. For example, P1 describes changing the verbosity levels in Soundscape: *"The first thing is Soundscape has different verbosity levels... Mostly, I'm curious to know about my navigation. So I have turned those extra verbosity levels off, I don't use them, I just want to hear about where I am, where I am heading to, or what is in front of me"* (P1).

However, there is still a desire for further customization of existing applications. For example, P5 described using the app Moovit [73] for navigating public transit, and wished that there was an additional setting where they could hear all of the intersections they passed as opposed to just the transit stops. Similarly, P8 described using various OCR applications to read text around them, and wanting to filter out only desired information:

> *'And even reading, for example, a piece of paper and you don't want to read everything on it. Just certain part, for example, you have a card, and you know where the card number is located. You just want that information.'* (P8)

In these scenarios, the assistive application lacked the specific customization options that would support participants' desired use.

4.2.2 Desired Modifications for Existing Assistive Technologies. When asked what they desired to change or customize in existing assistive technologies and why, participant's reasons generally fell into three categories: accuracy, efficiency and usability, and scope.

Accuracy and Model Construction. Many times, assistive technology cannot complete a task with the desired degree of accuracy. For example, with text recognition applications, participants commonly cited accuracy issues when reading diverse fonts on non-paper surfaces, such as the text on small LCD displays, or handwriting: *"I know Seeing AI and KNFB Reader, they're starting to do more handwriting stuff, and I'm like, It's not accurate. Okay, more accurate handwriting options. That would be wonderful because sometimes I want to read a handwritten note"* (P5). Other times, the assistive technology's underlying model is not built to capture the desired information or features, for example, highlighted text in a computer's BIOS: *"Sometimes you're stuck in the BIOS, and there's no way to know where you are. Right? The only problem where it doesn't work is it can't tell you what is highlighted"* (P6).

Efficiency and Usability. Participants often identified cases where an assistive technology seemed to have the technical capability to work as they desired, but it was not designed to support their needs. For example, P7 described wishing that Google Maps did not completely re-route them after making a wrong turn, so that they could follow a familiar route and use their orientation and mobility skills: *"When you do a mistake, it shouldn't reroute you... It should tell me to go back and redirecting me to the right route, to the first initial route"* (P7). Similarly, P2 described how they wanted Seeing AI to repeat text less frequently, as it often became repetitive as they moved an object around to try to find a specific piece of information: *"So to hold the the camera in such a position that it captures the labels accurately, is somewhat an arduous task. And I think that's where the app needs to improve a lot. Somehow, it hasn't really considered many of the test cases where blind folks are using cameras, right? Your hands might be shaking, and you don't know where to point directly, things of that nature. And I think because of that, there is a lot of inaccuracy in what it picks up"* (P2).

Scope. Occasionally, tasks seemed to be out of the scope of any existing assistive technology. For example, P1 described trying to use Seeing AI to find the model number of a vacuum cleaner for repairs, except they did not know where the number was located, if there were multiple numbers on different parts, or if the text would be faded. They described this inaccessibility: *"I believe that this application, like Seeing AI does not have the necessary affordances for such a scenario. This is not the fault of the app. This is the problem of the inaccessibility of the scenario, and I am trying to fit the application to solve that problem, right. But initially, that application does not have that affordance"* (P1). In this case, P1 did not desire to change Seeing AI at all, but rather: *"Instead of me thinking about designing the technology to solve this little problem, if I had the power, I would* *fight for policies for manufacturers, just to put a QR code on their appliance"* (P1).

Some desires for assistive technology modification fall into multiple categories. For example, participants mentioned that they were unable to read the text on digital displays, because text recognition cannot detect text accurately on glaring surfaces. This scenario spans both accuracy and usability, as it could be improved by providing users with guidance on how to better position their camera in order to deal with inaccuracies in the underlying model.

4.3 Design Through Use

We found that BVI people engage in assistive technology design through their use and modification of existing assistive technologies (RQ2). As P10 described, *"It's a lot of tinkering. Tinker, tinker, tinker."* Here, we describe three common strategies that we observed participants use in order to adapt to various gaps in assistive technologies: hacking, switching, and combining.

4.3.1 Hacking: Creating assistive technology through unique use. Participants often used assistive technology in a way that it was not originally intended in order to accomplish new tasks. The concept of sharing 'life hacks' is popular within accessibility communities, with people often sharing tips and tricks between friends or on social media [41, 68]. For example, P12 described a training group for blind people that shared how to make a phone stand to prop up the camera and more easily scan text: *"So this is another hack. I've never done this. But some people have made like a stand that you can sit your phone on, and then put something underneath it. So it sturdies the phone. They made it out of like some kind of plastic, they put a hole in like a plastic step stool. They were doing that at the at the training center"* (P12). This falls in line with previous examples of physical DIY assistive technology.

However, we observed that participants also developed their own unique workflows with assistive software. For example, P9 described using a workaround to read PDF documents on their phone that aren't accessible, because their mobile OCR application could only handle images: *"If I have an inaccessible PDF document, there is no software currently that does OCR on this if I really need to read something on the phone... so what I need to do is I need to take a screenshot of whatever page I want to read in that PDF document and then do OCR"* (P9).

In these cases, the unique uses of assistive technology often result in new design concepts. We aim to highlight the bespoke design work that is inherent to this behavior: as people discover ways to accomplish new goals, they often envision ways that they would change both current and future technologies. In this way, the process of using current and creating new assistive technologies are interconnected.

For example, P7 described using Lookout to identify obstacles while walking outside, even though it is not a navigation app: *"I knew there was a dog around me, but I didn't know where and I wanted to keep my distance from it. And I used Lookout to get its location. But, it's mostly for identification, not for localization"* (P7). When thinking about this scenario, P7 imagined how this task could be better supported, just by slightly modifying features that already exist: *"I think Seeing AI has this while Lookout doesn't, it can tell you position of things in the photo. So you can actually touch the screen and see where on the screen one particular identified item is. So that would be interesting. And maybe using–I just now realized but I'm not sure if it can be done–using the compass on the phone, it could try to tell you the position of things relative to my position. So that's 12 o'clock, three o'clock, you know"* (P7). Here, P7 demonstrates how unique assistive technology needs can spark ideation.

4.3.2 Switching: Switching from one assistive technology to another. Switching from one application to another was noted as another strategy to accomplish desired tasks. Much of this switching happens when one service fails to complete a task or is otherwise unavailable. This can be an AI service failing, as described by P12: *"Aira is my backup, so if like Seeing AI is just like spitting out gobbledygook and I can't make sense of it... Like, [Aira] is not my go to, it's not like my, the first thing that I'll pull out, like, I'll try to do it myself first"* (P12). P3 described a similar strategy, where they would use Seeing AI to skim written text to determine if they wanted to read it. If yes, they would call human assistance: *"In the instance that it does seem like I want to probe into that paper or label more, then I might switch over to say, Be My Eyes or Aira"* (P3). Alternatively, human assistance might not be available: *"That's one complaint is there's just not enough agents available to respond to calls... So I've gone back, okay, Aira's not an option, then I'll go back to Seeing AI"* (P12).

Switching also occurred as participants often downloaded multiple applications meant for similar purposes as backups. P8 described switching from Seeing AI to Envision AI for text recognition when one was not working: *"When there's Arabic, certainly, Envision is a better choice... And sometimes, I don't know why Seeing AI does not work, I would just switch to other way. It's just whichever comes first in the share sheet"* (P8). However, over time they became more familiar with the strengths of each service: *"At this point, I just know what would work and what will not work"* (P8). As P10 described, having different services just in case provides a sense of security: *"And I have to, I do like to keep them all, just because it's always good to have multiple apps that kind of do the same thing because you just never know, on one day where one will work and one won't"* (P2).

In other cases participants switched to new applications to complete different stages of a task. For example, P12 described using BlindSquare to navigate, but as they approached a destination, moving to Aira to be certain that they were in the correct place: *"[I was] using BlindSquare to get like within 100 feet of my destination, and then using Aira to identify, so I'm 100 percent sure that that was my destination"* (P12). Similarly, P2 described using both Seeing AI and a voice assistant while cooking: *"So I wanted to cook something. I had my cans with me. I figured out what I wanted to eat. So I fired up Seeing AI and I found the cans. But then I wanted to get the recipe how to cook it. Then I asked Alexa to get me the recipe. And it read out the recipe to me"* (P2).

While app switching behaviors are not uncommon within the general population of smartphone users [87], we highlight here how BVI people use switching to account for deficiencies in assistive technology. These instances of routinely chaining various assistive applications together could point towards the need for future automation methods to better support this behavior.

4.3.3 Combining: Using multiple forms of assistive technology at once. Another strategy that participants use to adapt existing assistive technologies was by using multiple forms of assistive technology at once. Participants used this strategy when they wanted to blend features from multiple apps. This was accomplished either by running one app in the background while actively using another, or by running both apps in the background and receiving audio alerts from each. Because assistive navigation applications heavily use continuous audio feedback, this strategy came up most commonly in navigation tasks. Audio features such as beacons in Soundscape, clockwise directions in Compass, live audio descriptions in BlindSquare, and route planning in Google Maps were all desired features that participants often wished to combine. For example, P12 described using the Compass app on iOS with BlindSquare in the background: *"I use BlindSquare and the compass a lot together. Just to make sure that I'm heading in the right direction. If I'm ever not sure... if I'm not on like a grid type pattern. And I found that to be the most beneficial, just to be able to give me a sense of direction"* (P12).

However, layering multiple applications like this comes with downsides. P6 described using BlindSquare plus another application for turn-by-turn directions. They noted that this worked, but it was not ideal: *"If they can integrate the actual direction finding [into BlindSquare], so you didn't have to run two apps at the same time, that would be nice. That would involve, you know, purchasing maps and probably make the app a lot more expensive. And you've got other apps on your phone that can do that for you. So I don't think that's necessarily that critical."* (P6). This was primarily because it is tedious to start and set up both applications.

Other participants also noted that while using multiple apps at once could be useful, it is too tedious to be a practical solution, and can impact safety: *"But using them together? I'm not that smart. Because, you know, a lot of cognitive or audio capacity should be used for each of these tasks, each of these apps. And when you're doing a task, and especially when I am outside? I don't engage myself in many of these apps, because I don't want to get distracted and put myself in any kind of danger. Especially when I'm navigating"* (P1). While different types of audio feedback are useful, they need to be carefully balanced to avoid overload. This is made more difficult by the fact that some applications provide audio feedback, regardless of other system audio. As P5 described: *"[BlindSquare] clashes a lot. That's my biggest problem with it. Like they want to include their own voice over sometimes. But I think it just kind of clashes with the built in one"* (P5).

4.4 Designing and DIY-ing Future Assistive Technology

In each interview, we asked participants to imagine DIY-ing new assistive technology in the future. Participants envisioned creating a wide range of assistive technologies, ranging in their purpose, scale, motivation, and technology (RQ3).

4.4.1 Scale. Participants' ideas for future assistive technologies varied widely in their scale. Some participants preferred to think about improving the technologies they already used, by fixing bugs, tweaking, or adding features. As P3 put it: *"I don't think it's always about necessarily creating novel assistive technologies. It's more about I would, if I had the skills and knowledge want to improve my user experience in life, if that means squashing accessibility bugs"* (P3). In comparison, other participants were more ambitious or dreamy with their ideas. For example, as P4 introduced an idea that they had come up with, they said: *"One of those things that I sort of envision in a way is, this might be a little, little too ambitious, I'm very ambitious in a way. It's not exactly like, like a tiny feature, let's say maybe, I don't know, maybe [a service] that looks at [an ingredient] and tells me interesting recipes. That could be great. But I think I'm looking at a very high level, more visionary"* (P4). This variation in desired approach could be seen as a part of the long-tail problem, and we discuss further how to support these desires in Section 5.1.

4.4.2 New Technologies. Participants envisioned including a range of technologies in their future applications, from devices that they currently owned (such as smartphones, smartwatches, or headphones), to other existing devices (such as 360 degree cameras, 3D printers, NFC tags, or AR/VR headsets), to devices that do not yet exist at desired form factors or with the desired sensors (such as future smart glasses or smart rings).

Participants also commonly described wanting to interact with technology in new ways, such as through verbal commands. For example, P1 described modifying Seeing AI to more quickly find a specific piece of information when reading text: *"For example, I could verbally tell Seeing AI, find expiration date on what you're reading, and don't read anything else, or find the shipping address on this piece of text. You are smart, right? You say I am using machine learning and whatever. Okay, go and use it. Listen to me and find the address or find the phone number on this or whatever. Yeah, that would be awesome"* (P1). P4 described a similar conversational approach to understand the space around them, and imagined using a 360 degree camera in their home to find objects that were out of place: *"I need to, like, actually understand, what does my house look like today? Like, what are the waste items around me? What are the things I see around me? Of course, I'm not saying that every little trinket... But then, maybe if there was a way where, if there was a camera, one 360 degree you know, visualizer that could like map once a day, or like, however many times I want today. And then it would tell exactly. Tell me, what are the weirdest things I have around me? Then, how far are they from where the camera was positioned? It would sort of help me understand and visualize"* (P4).

4.5 Opinions on a DIY Assistive Technology Process

The concept of DIY-ing new assistive technologies was interesting to participants, who envisioned many potential benefits and pitfalls (RQ3). We describe those here.

4.5.1 Past Experiences with Creation. Participants had a range of past experiences with designing, building, and otherwise contributing to assistive technology creation. On one end of the spectrum, four participants reported having previously programmed or attempted to program some form of assistive technology. For example, P7 created one of the most downloaded NVDA add-ons, as well as a variety of macros for their own personal work efficiency; P0 created a program to record online lessons; and P6 created a speaking HAM radio. Participants also described modifying existing objects, consistent with existing work on DIY assistive technology, for example, P11 customized a board game using Braille labels, and P9 described creating a makeshift signature window.

Aside from directly creating assistive technology, participants also contributed to assistive technologies in other ways. One method was in creating bug reports or making feature requests directly to developers. For example, P0, P3, and P10 described having done this in the past. P3 also described the process of working directly with their university administration to complete and beta test Open Street Maps data for their campus. However, bug reports are often an inadequate solution for accessibility, as P10 noted: *"Every once in a while, if you're persistent, you can get things fixed. But you really do have to be very persistent and have specific things that you can tell them. This is what it's doing. You know, and you could fix it this way. You can't just complain, you have to actually have a very specific description of the problem and get the right person that understands that to get it fixed"* (P10).

Aside from bug-reports, another method was in being involved in research studies. P4, P5, P6, and P12 all noted their involvement in past research studies, and described trying to encourage others with the appropriate skills or resources to put their ideas into action. As P5 noted: *"I've done a lot of research studies in the past, especially with like, human centered computing, and accessibility, like all that stuff allows me to think and to imagine... I just feel like I'm very deliberate with who I tell about the ideas"* (P5).

4.5.2 Value of Creation. Participants saw the act of creating new assistive technologies as valuable in a variety of ways.

As noted in the previous section, many participants were motivated in the past to create things that met their specific needs. Thus, part of the value in DIY-ing assistive technologies is in allowing people to personalize things for themselves. P1 made an analogy to modifying recipes to one's taste: *"That would become like a cooking recipe. And then people could contribute with that. Like with recipe books, the person can also modify that recipe towards their need, like when you are like cooking your own mushroom soup. It may be you change it to your taste"* (P1). Similarly, P11 said: *"I would create for me, but even for other people. And I think that the value is that you can personalize as you wish, because sometimes, of course, you have an assistive technology, but it's not really personalized. I mean, this technology has to be made, according to the preferences of many people. In this case, I will to do it with my preferences, and what I want it to be"* (P11). This highlights that while assistive technology is typically developed according to the needs of many, there is a potential for tailoring to individual needs. P5 also noted how someone's background could affect these preferences: *"We all have different vision. And we all have different ways of navigating life. So we want to make sure, like me, I'm more of an advanced traveler. So if I were creating an O&M device, I wouldn't need a basic one. I would want something that could go with me on what I do on a daily basis"* (P5).

Relatedly, DIY assistive technology would allow people to act on their existing ideas and bring them into reality. Often, participants described putting a lot of thought into their ideas: *"This is something that's been on my mind"* (P9), or *"I'm so passionate"* (P5). However, aside from encouraging others to make these ideas into real services (*"I did go along the lines of encouraging one of my past companies on building an app"* (P4)), these ideas are mostly left unrealized.

Finally, participants believed that enabling DIY assistive technology approaches would be beneficial for crowdsourcing ideas on a larger scale. For example, P10 said: *"I don't have any programming experience. But I think if you're giving the tools to work with, say you've got this, this, and this. Then see what you can do with it, I love it"* (P10). P9 expressed a similar sentiment, adding that it would give people more agency: *"You never know, people might just be doing some trial and error and something great might just emerge. So you're giving people all of the ingredients and they can make whatever they want out of it. Certain times it might turn out to be really nice, certain times it might not. Which is fine, at least people have the choice"* (P9). Specifically, blind people could be enabled to share their ideas and experiences with other blind people more widely: *"And I think a shareable repository type, like, the Siri shortcut store. That could be really interesting approach. Because currently, there is no platform that I'm aware of where blind people or other people with disabilities can, you know, share their customizations"* (P0).

4.5.3 Concerns About Creation. One major concern that participants had about creating their own assistive technologies was being able to understand the functionality and limitations of technology. As discussed, many participants had grand visions for the future technologies that they desired, but noted that they would need to understand what is possible before creating. For example, P3 described creating an indoor navigation application around what AI can reliably detect: *"I would probably need to learn more. Probably there are stairs and then maybe a door and a bunch of other things, I would try to list those. Then figuring out which of them are easiest to expect an AI as we have it today to be able to simulate, and then implement those"* (P3). As P6 described, knowing what technology can and cannot do is important when envisioning new applications: *"You better have some way to get support or to know what you actually can do with it"* (P6).

However, this is a challenge even for those that are familiar with programming, due to the visual nature of most AI-based assistive technologies. As P7, a professional programmer, described: *"I think this is a little bit of above my head. I'm not very good with AI. And I'm not really good, especially with images. So I'm not sure why those system fail, and not knowing why they fail, I can't tell if they could work better in these situations"* (P7). For example, they described wanting an assistive technology that could tell them if something was clean or dirty in their home, but not knowing how to approach the problem: *"I really don't know exactly what's needed. Because I don't know how things should look, or look when they're dirty or not. So I didn't really know how this should be performed"* (P7).

Multiple participants suggested that providing ways for people to collaborate and learn from each other could work to address this, and that they would not want to work alone on new assistive technologies. For example, P5 noted that coaching and collaboration would be key to guiding the feasibility of their ideas: *"When I say coaching, I don't want someone to come in and say, no, this is how you have to do it. But there needs to be a professional, I'd say maybe even an advisor who can say, you know, you want to do all these things. But I want to let you know that right now, given the technologies that we're working with, it's not even feasible to do such a thing. Because it's great to imagine, but it's not great to start based off something that's unrealistic"* (P5).

Alternatively, other participants preferred to contribute to new assistive technology by providing design suggestions and feedback, rather than implementing. As P12 described: *"I mean, could I see myself maybe as part of a focus group? Or a think tank? Or something like that... And I feel like maybe that's where I do the best kind of brainstorming"* (P12). As P10 put it though, this could also be due in part to not having the opportunity to create things in the past: *"I guess I haven't really thought of it. Because it's just one of those things that you, you leave to the experts and hope that they get what you want. And someday, you know, but I never really thought about creating it myself. I think it's an amazing concept, though"* (P10).

Going past these concerns about the approachability of creation, others had more logistical concerns. Some worried that the small potential user base of such tools would lead to low adoption, and thus tools becoming defunct over time. P6 described the challenges involved when an assistive technology they have come to rely upon loses business and is no longer available: *"They made something for the GE washing machines that would talk and tell you what cycle it was in and how much time there was left. And they did it through one of those maker shops that had it manufactured, but the problem with that is it existed for about a year or two. And either they ran out of money or couldn't make money on it or whatever. So now the product is not available, but the washers are still being made. We actually have one of them but I can't use it because there's no way to get this product"* (P6).

Finally, while better supporting DIY assistive technology creation could be beneficial, as P1 noted, it could also further place a burden on disabled people to fight problems with the inaccessibility of the world: *"Why do assistive technology researchers or designers put all the effort and burden on their shoulders to fight the inaccessible world, this is impossible. Because you see, everybody is doing what they want to do. And we should follow them to add here, and glue layers of accessibility on top of it? And at the end of the day, it will never be naturally usable"* (P1).

5 DISCUSSION AND FUTURE WORK

In this work, we characterized the strategies used by BVI people to customize and adapt their assistive technologies to unique needs. Supporting DIY creation of high-tech assistive technologies could further support and enable these behaviors, and thus work to meet the range of unaddressed assistive technology needs encountered by participants. Participants were generally enthusiastic about being involved in DIY assistive technology creation, though they envisioned a range of barriers to doing so. In this section, we first discuss future considerations for those barriers, supported by both participants exisiting behaviors and by prior work. Next, based on these considerations, we discuss the feasability of one potential approach to DIY-ing assistive software: end-user programming. Finally, we summarize some of the limitations of this work and make suggestions for future studies.

5.1 Design Considerations for Supporting DIY Assistive Technology Creation

From our results, we present design considerations for how existing and desired customization behaviors could be supported by DIY technology creation tools in the future. These considerations were generated directly from our study findings, and are supported by prior work in accessible programming, DIY technology, and collaboration.

5.1.1 Approachability and Accessibility of DIY Creation. As described in Section 4.5.3, many participants believed they did not have the technical skills to create new assistive technology, with the current landscape of tools generally requiring programming experience and a technical understanding of what various sensing systems are capable of, as described by P3. Participants were still optimistic about being involved with technology creation in the future, and believed they could if they had guidance on how to program. Thus, one key concern when designing systems to support DIY assistive technology creation in the future is designing for a range of technical experiences and backgrounds.

This is a known issue in the DIY technology space, for example, years of research have been dedicated to making advanced 3D modeling and printing more widely available and approachable as a method [33, 34, 52, 52, 74]. The same challenges also apply in the cases of creating higher-tech DIY assistive technology, thus, these cases will also require future research to design approachable systems to support creation.

However, assistive software development poses some specific challenges. Even for professionals, blind programmers face a variety of challenges when developing software (e.g., working with inaccessible software environments, navigating programs) [4, 81, 91]. Though there have been a variety of tools developed to address these issues [10, 58, 85], systems that are aimed at non-experts (like block-based programming or other simplified programming interfaces) currently lack accessibility [71, 75, 76].

5.1.2 Different Roles and Collaboration. Through our study, we found that participants contributed to existing assistive technology design in a variety of ways, and thus had a range of preferences for contributing to DIY assistive technology in the future. We described participants active contributions to the design of assisitive technologies through both their ongoing customization and hacking (see Section 4.3), and their explicit creation efforts such as programming, making feature requests, or participating in research studies (see Section 4.5.1). These varying roles and strategies are important to support in future DIY approaches.

For example, as one potential avenue for contributing to DIY assistive technology in the future, the majority of participants were receptive to the idea of contributing more formally to an existing repository of assistive technologies that they could then modify for their own use if needed (see Section 4.5.3). This could result in a more formal 'community of practice' as coined by Lave and Wenger [61], in which members of the community could engage in legitimate peripheral participation, where novices become acquainted with the tasks, terminology, and knowledge of a community by building up from simple tasks. Thus, supporting a repository of this type could address issues of approachability, allow BVI people to share solutions, and support a range of desired community roles that play to different strengths and desires of community members.

Other participants also noted specifically wanting to collaborate with others who had the technical skills to create something (see Section 4.5.3). These participants, P5 for example, wanted to help more by making design suggestions to a small group, but less by 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.

ACKNOWLEDGMENTS

We sincerely thank our participants for their time, and for sharing their expertise and experiences. We also thank our reviewers for their time and feedback. This research was supported in part by a Google Research Scholar Award. This material is based upon work supported by the National Science Foundation Graduate Research Fellowship under Grant No. DGE-1841052. Any opinion, findings, and conclusions or recommendations expressed in this material are those of the authors(s) and do not necessarily reflect the views of the National Science Foundation.

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