Cooperative Privacy and Security: Learning from People with Visual Impairments and Their Allies

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Abstract

To better inform privacy/security designs for people with disabilities, we "shadowed" people with visual impairments and their allies (e.g., friends, family members, and professional helpers) for two days followed by an exit interview. Our study results provide rich and nuanced accounts of how people with visual impairments enact their privacy/security in daily life, influenced by both their interactions with their allies and multiple (marginalized) dimensions of their identities such as different disabilities. We also found that people with visual impairments often work closely with their allies to protect their privacy and security in a cooperative manner. However, they were also thoughtful about who they would ask for help in part due to privacy reasons, even if they are trustworthy family members. We discuss ideas for future research and design, particularly a need for designing mechanisms or tools that facilitate cooperative privacy management (e.g., between people with visual impairments and their allies).

1 Introduction

The majority of end-user privacy/security mechanisms rely on visual cues, such as checking the lock icon for secure web connections (HTTPS), and scanning the environment for physical security threats. These approaches are challenging for people with visual impairments, which include people on a spectrum ranging from low vision to complete vision loss, and in some cases co-existing with other disabilities. We also agree that "disabilities need not to be fixed but are assets in their own right" [45]. Historically, disability is defined by a "lack of ability, knowledge, etc" and often technologies are seen as a means to fix this so called "lack of." Instead, we are challenging this notion by looking at the experiences of disability as socially constructed and valuable to improving technologies and systems rather than the opposite.

Our long-term research goal is to design effective privacy/security mechanisms to better support people with disabilities. To help inform future design, we conducted an observational study involving adults with visual impairments and their allies (e.g., friends, family members, professional helpers) to answer two main research questions:

- RQ1. What are the everyday privacy/security challenges and practices of people with visual impairments?
- RQ2. How do people with visual impairments interact with their allies? What are the privacy or security implications of such interactions?

We use the term *ally* to explore the complexities of social relationships between people with disabilities and those who respect and often interact with them. We use ally rather than caregiver because the latter implies a one-sided relationship whereas the former implies "equality, mutual trust, and shared decision-making" [20]. In our research, we sought to bring a marginalized group to the center [17] and therefore individuals with visual impairments were the primary focus of our study. We also explored their relationships and interactions with allies, many of whom also participated in our study.

Compared with prior work on privacy/security practices of people with visual impairments (e.g., [3,4]), the novelty of our research is twofold. First, from a methodological perspective, we employed an observational technique (i.e., "*shadowing*" participants [34, 48]), complemented with semi-structured interviews to understand participants' lived everyday experiences. Analytically, we paid special attention to how our participants' everyday privacy/security experiences are shaped by their interactions with allies and by different (marginalized) dimensions of their identities such as disability and gender identity ([35]). Second, our study provides novel findings

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regarding participants' views of their own visual impairments and their conceptualizations of privacy. Both may influence their everyday privacy and security practices (e.g., disability disclosure and willingness to ask for help). We also uncover understudied privacy/security challenges participants faced (e.g., managing social relationships, sharing information with their allies under organizational policies). Our results also suggest that privacy was a key factor in considering who they would ask for help, including trusted family members.

Our findings lead to two key takeaway messages for future privacy research and design. First, *privacy management can have an inherently cooperative dimension*. As our study highlights, people with visual impairments often work closely with their allies to protect their privacy and security. Second, *privacy tools designed with underserved users in mind should pay attention to multiple marginalized identities these users might have.* As we saw in our study, some participants have other disabilities or marginalized identities. Their lived experiences are not only influenced by a single identity (e.g., visual impairments) but by the intersecting effect of all marginalized identities. Designing mechanisms to support this type of cooperative privacy management while considering the various marginalized identities of underserved users is a worthwhile direction for future research.

2 Related Work

In this section, we review prior work on privacy/security challenges for people with visual impairments and the roles that allies play in the lives of marginalized groups.

2.1 People with Visual Impairments

A few studies have focused on privacy/security issues for people with visual impairments. Many privacy/security threats arise from the use of accessible technology, as these devices inadvertently generate new avenues for passersby to learn personal information. People with visual impairments have concerns about aural and visual eavesdropping in public when using screen readers and screen magnifiers, respectively [7, 19, 30, 37]. Prior work also suggests that this user group may not notice privacy/security risks in their environment or inherent in the technology they use [14]. The use of accessible technologies can also draw unwanted attention and potential exploitation [44]. To mitigate some of these issues, people with visual impairments use privacy features (e.g., iOS Screen Curtain) and wear headphones to mitigate problems with screen readers [53]. Ahmed et al. identified privacy/security concerns or challenges people with visual impairments face such as difficulties verifying the security of banking or shopping websites, maintaining privacy on social media, asking strangers for help [3] and physical safety/security challenges in public spaces and at home [4]. Our study sheds new light on how people with visual impairments think about privacy as well as how their privacy/security experiences are shaped by their (marginalized) identity dimensions (e.g., multiple disabilities) and interactions with allies.

2.2 The Roles of Allies

People with visual impairments, particularly those who are blind, often have allies who assist them in various aspects of their lives. Previous research suggests that various challenges for people with visual impairments [32] are impacted by allies. For instance, Paisios et al. note the ways in which the visual nature of banking has left people with visual impairments reliant on the kindness of strangers, which can ultimately be a risk and fail to allow for independence from these individuals [39]. Kröger explores the intersection of ally research and disability theories and suggests treating both people with visual impairments and their allies as participants, exploring how their relationship can contribute to structural issues including autonomy [32]. Prior research has also suggested allies' concerns about maintaining the privacy of those they interact with. For instance, in an interview study of older adults and their allies, the latter were found to heavily rely on routines (e.g., older adults sending daily email check-ins) to manage the tension between their need for awareness and the older adults' need for privacy [11]. Systems that enable routines aligned with the allies' goals could, therefore, receive wider acceptance [11]. Prior research also suggests people with visual impairments are keenly aware of being perceived as a burden, and may wish not to depend on friends, family members, or other people [15]. While these studies provide valuable insight into how some underserved groups and allies collaborate, the privacy-related practices and implications of allies interacting with people with visual impairments remain understudied. Our results include observations of adults with visual impairments and their allies, shedding light on the privacy/security implications of their interactions.

3 Study Methodology

Unlike previous research, which was mostly based on interviews, this study employed two rounds of passive observations during a weekday and a weekend day, focusing on how our participants go about their everyday lives. We believe that our observational approach is appropriate because this method strikes a good balance between the acceptability/manageability for our participants to be observed as well as grasping their diverse and multi-faceted lived experiences embedded in rich social settings. We also conducted semi-structured interviews with our participants to complement the observations. The study has been approved by our IRB.

3.1 Participant Recruitment

From August 2017 to April 2018, we recruited adult participants in a metropolitan area in the Northeastern part of the US via email, phone, flyers, newsletters affiliated with local disability organizations, and attending monthly meetings with a local group of people with visual impairments. We also encouraged participants to recruit their friends and/or family members via snowball sampling [10]. Due to the nature of our study (e.g., extensive observation), we found recruiting participants to be a significant challenge. We recognize our small sample size as a key limitation, which prevents us from generalizing our results. However, similar to qualitative studies in general, our study provides rich accounts of people's lived experiences, which large-scale quantitative studies hardly offer. We were interested in the "richness" of their experiences rather than the commonality of these experiences. We created a pro-rate scheme to compensate our participants up to $60: initial interview ($5), first observation ($20), second observation ($20), exit interview ($5), and full completion of study tasks ($10). Both our participants with visual impairments and ally participants read and signed consent forms before the study. All participants completed the entire study.

3.2 Build Trust with Disability Communities

For more than a year before this study, members of our team were invited to and have been regularly attending monthly gatherings of a local group of people with visual impairments. Our research team has also volunteered in many social events hosted by this group (e.g., BBQ parties). In addition, we were invited to subscribe to their email mailing list. With their permission, we used this mailing list to distribute our recruitment materials to the group. All interactions with this group allowed us to get to know each other and build trust with them. Three of our eight participants came from this group. We also attended meetings involving a group of local military veterans with visual impairments and presented this study to them. Two participants came from this veteran group.

3.3 Other Ethical Considerations

Following suggestions from prior work [27], we told our participants that they could pause our observations and/or quit the study at any time. Upon participants' explicit permission, we audio recorded every session. We also verbally notified each participant when we started each audio recording. We allowed the recording to continue throughout the entire session, including the interview and observation portions of each study session. The only exceptions included travel between observation sites (e.g., from work to home) or our observations of participants conducting an outside activity (e.g, walking in a park). To ensure correct understanding of participants, we reviewed the main points we learned from our participants to clarify any misunderstandings we might have. We also sent a draft of our paper to our participants for feedback.

3.4 Study Protocol

We set out to study both adults with visual impairments and their allies. We told our prospective participants that we are interested in learning their experiences in daily life in order to understand their privacy/security needs and to inform technology designs that can better support people with visual impairments. This study has five main components: an initial interview, a weekday session of observation, a weekend session of observation, a set of pre-defined tasks in one observation session, and an exit interview. We include the study script in the Appendix. In all cases, two researchers conducted the study: one led the session and another took detailed notes.

The study started with an initial interview, in which participants were asked to describe themselves including their demographics (e.g., age bracket, gender identity, occupation), disability identity if they had any, what their daily life looks like (e.g., normal schedules, activities), and their general experiences with computing technologies and the Internet (e.g., computers, mobile devices, accessible technologies). We also asked allies about their relationships with our individuals with visual impairments and various tasks with which they often assist. This initial interview provided us relevant background information about our participants.

We then conducted observations of participants for a few hours per session (ranging from 2 to 8 hours, ending upon participants' requests): one during the week and another on the weekend, respectively. This ensured that we could learn about their lives and practices at home and work (if applicable). The observations were done using a *shadowing* method, which means that researchers follow and observe participants while taking note of what participants were saying or doing. Shadowing has been demonstrated as an effective way of gathering rich and in-depth qualitative data in the HCI community [34,48]. Since our goal was to gain a deep understanding of participants' privacy/security practices in everyday life, shadowing allows us to embed ourselves in the cultural and social settings of our participants' lives. We attempted to make our shadowing as unobtrusive as possible and informed our participants to behave as they normally would. When possible, we shadowed individuals with visual impairments and their allies simultaneously. However, at other times we shadowed participants with visual impairments without their allies due to scheduling/availability issues associated with them.

Throughout each observation, we took detailed notes using a template we designed. This template included fields for the start/end times and location of each activity we had observed, presence of other people, use of commodity and accessibility technologies; involvement of others (e.g., allies) in the activity; any privacy or security challenges encountered; any information being exchanged between individuals with

visual impairments and their allies and any hesitation each participant expressed in seeking help or relaying information.

We observed our participants conducting various activities such as grocery shopping, walking in a park, depositing money, checking mails, giving lectures, working on assignments, playing online games, using social media, receiving mobility training, doing laundry and using home appliances.

At the end of the second session, we asked our participants with visual impairments to perform or demonstrate a short list of pre-defined tasks. These tasks prompted participants to demonstrate how they use their technologies everyday, focusing on computers and/or mobile phones. A few examples included using their email and social media and demonstrating use of accessible technologies. We asked our ally participants to describe in detail how they assist individuals with visual impairments with the activities they reported in the initial interview. We wrote memos reflecting what we learned from each session and met regularly to discuss our notes.

Lastly, during exit interviews, we inquired further about the experiences of our participants with visual impairments in asking for assistance. We probed allies specifically about potential access to more personal information than needed, feelings of regret in providing help, and times when they became responsible for the privacy of those they work with. We then asked all participants a short set of questions about their privacy attitudes, concerns, and solutions. We also asked them for feedback about the study.

3.5 Analysis

Field notes and interviews were the primary sources of data for this study. We used memoing [25] to reflect our observations and conducted a thematic analysis [13]. After collecting and reviewing all audio recordings and participant interactions, we held weekly meetings to discuss our notes. Four researchers independently reviewed our collected data multiple times to gain a general understanding of each participants' experiences. Next, each researcher completed a round of open coding for the same two participants, deriving codes directly from the data rather than applying an established theory. We then collectively discussed the individual coding schemes and converged on a shared codebook to code the rest of our data. Next, we had another round of group discussion to walk through every participant's data and coding. We then explored higher-order connections between codes using affinity diagrams [16]. We identified notable themes, such as participants' views of their disabilities, their definitions of privacy, their awareness of/response to security and privacy threats, and relationships and interactions with allies in their everyday lives. We then had another set of group meetings to discuss and interpret the examples from our study with an eye on underlying factors such as agency and trust.

3.6 Participant Background

We had a total of eight participants, including three blind participants (P1, P2, P5) and two participants with low vision (P3, P4) as well as three allies (A1-P1, A2-P2, A3-P5, allies of P1, P2, and P5, respectively). We asked P3 if he was comfortable with us asking his wife (ally) to be part of the study, but he refused because he wanted to be as independent as possible. Since P4's ally (her daughter) is not an adult, we cannot have her as a participant due to our protocol. We conducted a total of 13 observation sessions, where during six sessions both participants with visual impairments and their allies were present. Table 1 summarizes the demographics of our participants. Table 2 shows the time, location, and whether allies were present at each study session.

4 Privacy/Security Perceptions and Practices

In this section, we first focus on how our participants with visual impairments viewed their disabilities, and how they thought about what privacy and security meant to them. These perceptions influenced their behaviors. We will then present how they dealt with their privacy and security both online and offline in their everyday lives.

4.1 Self-Perceptions of Their Disabilities

To understand the everyday experiences of our participants with visual impairments, we observed how they viewed their disabilities. We checked with our participants to verify these descriptions. Self-perceptions are important because they can influence our participants' behaviors, which may have significant privacy and security implications such as hiding or concealing their disability identities because of perceived stigma; this is known as visibility of disability identity [21].

P1 is a student in a US university and is originally from Tanzania. He was born blind and lives alone in an apartment close to campus[1] He has a part-time job in which he helps with issues associated with accessible technologies. He often hangs out with a friend from work (our participant, A1-P1, an African American office manager). He sometimes asks A1-P1 for help, e.g.,grocery shopping. P1 was open and accepting of his disability and has a preference for independence. For instance, instead of asking A1-P1 for help, P1 has recently started using Uber to go places by himself.

P2 is a Caucasian Reiki master who lost her sight completely in a shotgun accident in 2009. She lives with her two children and mother (our participant, A2-P2, a Caucasian office worker), who she frequently asks for help completing various tasks such as grocery shopping, using email and managing her bank account. P2 referred to her loss of vision as "*being constantly in a big black box.*" She also self-identifies

[1]We understood this description could reveal P1's identity. We checked with P1 and he actually preferred this description than a less specific one.

Table 1: The upper part of the table shows the participants with visual impairments (P1-P5), their gender identity, age, marital status, self-described disability or health status, and use of the accessible technologies. The lower part of the table shows the ally participants (A1-P1, A2-P2, A3-P5 are allies of P1, P2, and P5, respectively). For allies, the last two columns represent the social relationship they have with their partner, and the kinds of help they provide (other activities include shopping, navigation, online ordering, household chores, etc), respectively.

ID	**Gender Identity**	**Age**	**Marital Status**	**Self-Described Status**	**Accessible Tech Use**
P1	Cisgender Male	30-40	Single	Blind	JAWS, NVDA
P2	Cisgender Female	30-40	Relationship	Blind, bipolar disorder, learning disability	VoiceOver
P3	Cisgender Male	80+	Married	Low vision, physical health condition	Dragon NaturallySpeaking
P4	Cisgender Female	40-50	Divorced	Low vision	ZoomText, VoiceOver
P5	Cisgender Male	60-70	Married	Blind, hard of hearing	JAWS
				Relationship	**Assistance Provided**
A1-P1	Cisgender Male	40-50	Single	Friend of P1	Shopping, Navigation
A2-P2	Cisgender Female	60-70	Married	Parent of P2	Banking, Other activities
A3-P5	Cisgender Female	50-60	Married	Spouse of P5	Banking, Other activities

Table 2: Details of the study sessions for each participant.

ID	**Session 1 (S1 time)**	**Session 1 (S1 location)**	**Session 2 (S2 time)**	**Session 2 (S2 location)**	**Ally present**
P1	8/22/17 10am-4pm	P1 office, apartment	9/9/17 12-4pm	P1 apartment	Mobile trainer (S1)
P2	9/28/17 2-7pm	P2 home, friend house, park	12/3/17 2-6pm	P2 home	A2-P2 (S1, S2)
P3	12/15/17 8-11am	P3 home, medical office	4/14/18 10am-12pm	P3 home	None
P4	2/22/18 11am-3pm	P4 home	3/13/18 3-5pm	P4 workplace	None
P5	2/28/18 12-4pm	Campus library, parking lot	3/17/18 11am-5pm	P5 home, hospital, shop	A3-P5 (S1, S2)
A1-P1	9/14/17 3-5pm	Workplace of P1 and A1-P1	10/1/17 3-5pm	Mall	with P1 (S2)
A2-P2	9/28/17 6-8pm	P2 home, friend house, park	12/3/17 2-6pm	P2 home	with P2 (S1, S2)
A3-P5	2/28/18 12-4pm	Campus library, parking lot	3/17/18 11am-5pm	P5 home, hospital, shop	with P5 (S1, S2)

with bipolar disorder and a learning disability. She struggled with using accessible technologies. For instance, she said, "*I can't use JAWS. I just hate that voice, it's so annoying.*"

While prior literature has studied online self-disclosures about stigmatized experiences such as pregnancy loss [5], our study observed whether and why our participants with visual impairments may choose not to disclose their disabilities. For instance, P3 is a retired Caucasian educator with low vision who lives with his wife and asks her for help completing daily tasks. P3 also has a serious health condition requiring him to receive medical treatments several times a week at a local hospital. P3 said he has: *"macular degeneration, continuous loss of the 'center of things;' vision loss starts at the center and then generally progresses through time."* He also said that he struggled with answering a large number of emails due to his low vision, but did not want to broadcast his visual impairment. He explained: "*They are not astute enough to know that I can't read it. And what I am gonna have to do is to contact the people I really want to hear from and tell them that they better call me.*" P3's decision not to broadcast his visual impairment has a practical utility of helping him manage his communications. He only wanted his important contacts to know about his difficulty of viewing emails. As such, he was selectively disclosing his visual impairments.

Prior literature has suggested that using accessible technologies might trigger questions about people's disabilities (e.g., [44]) and make them more vulnerable in public places (e.g., [4]). We found that hiding one's visual impairment is also a way to protect themselves in a public environment. For instance, P4 is a Caucasian disability coordinator with low vision who lives with a housemate and one daughter. She does not drive on her own, and therefore relies on others such as her housemate and co-workers to provide transportation. P4 mentioned that if she needed help to read something in public, she would often hesitate to disclose her visual impairment. Instead, she would say: "*I forgot my glasses at home, can you help read what this is?*" These behaviors may reflect their personal insecurities that can stem from a generally accepted notion of society that they are not part of the mainstream [24].

Similar to prior literature (e.g., [4]), we found such fear of insecurity can also motivate a person with visual impairments to seek help from trusted allies. For instance, P5, a Caucasian retired doctor and a veteran, became blind due to a motorcycle accident. He is also hard of hearing and uses a hearing aid device. He lives with his wife (A3-P5, a Caucasian home-maker) and was heavily dependent on her for grocery shopping or visiting hospitals. He often avoided accepting help from strangers or even friends because of a lack of trust.

4.2 Self-Definitions of Privacy

There are many but no agreed-upon definitions of privacy [47]. Instead of defining privacy for our participants, we asked in the exit interview how they would define privacy in their own words. While our participants' privacy conceptualizations were not necessarily new, we note that prior literature rarely covers this aspect for people with visual impairments. Knowing their definitions of privacy can help us unpack their privacy concerns and practices. Three participants (P3, P4, and A1-P1) defined privacy in terms of ownership and control over their personal information. For example, according to P4, privacy meant "*keeping your personal information to yourself; keeping things to yourself that you don't want other people to know.*" Such control over their personal information can also provide them a sense of security. For example, P3 referred to privacy as "*the ability to conduct life confidently and securely, knowing that I will not be surprised by someone telling me things about myself that I have never shared.*"

A1-P1 attempted to define privacy in the context of his "allyship" with P1. He viewed personal information as one's own property and privacy as a right to such property. He explained, "*Things that are private to an individual should remain private unless otherwise stated by the person who owns the rights or the property.*" A1-P1 then gave an example: if P1 asks for help, then he helps but otherwise laundry is his private property and P1 knows how to handle that himself.

Other participants' conceptualizations of privacy focused on "the right to be let alone," a classic definition of privacy proposed by Warren and Brandeis [47]. For instance, P2 felt that privacy could also mean "*alone time privacy.*" Lastly, P5 touched upon the sensitive yet crucial relationship between individuals' privacy and society. According to him, privacy also included, "*acceptance by others of me saying I don't wish to share that info and then in turn, respecting my privacy.*" Overall, these definitions shared a desire of agency and control over one's information and ways of living. With this understanding of our participants' privacy conceptualizations, we now discuss their applications to daily life.

4.3 Privacy/Security Concerns and Practices

Similar to the findings of prior work (e.g., [3, 4, 7]), our participants with visual impairments expressed many concerns about privacy and security while using technology on a regular basis, in home, work and public settings.

Home settings. We observed some deceptive practices (e.g., scams and malicious software) that plagued our participants with visual impairments. For instance, while conducting the pre-defined tasks portion of our first study session, we asked P1 to demonstrate logging into his email client. During this task, we observed a fake virus warning pop up in his browser. He was unaware of what had happened but just asked, *"what's wrong?"* While any Internet user might click and fall prey to these types of fake warnings, people with visual impairments might be even more vulnerable because they might accidentally click the warning especially if the screen reader does not recognize its existence.

Work settings. Our participants were concerned about their private information being inadvertently stolen or compromised on the job, mainly due to enlarged screens or accessibility features leaking private information. For example, during the scenarios portion of P4's study session, she provided us with an instance where she was concerned about shoulder surfing. P4 stated that her work iPad screen is a lot bigger than her phone, thus has the potential for people to easily see her private information. She explained: *"When you have such a big screen, you can't sit there. Most people can do personal stuff, you know, you could see what I'm doing."* She would only check private information in her office.

Public settings. Our participants were also concerned about leaking their information in public and adopted various protection strategies, e.g., using earphones while using the screen reader on their phones to check emails, or during ATM withdrawals. However, they also felt it is more challenging for them to hide their information than people without visual impairments. For instance, P4 elaborated during the initial interview that many adept smart phone users without visual impairments can easily check or send a text under the table or otherwise out of sight, but that is not something that she can do. While smartphones have built-in accessibility features (e.g., Android screen reader, iPhone screen curtain to black out the phone screen) for users with visual impairments, they still lack accessible features supporting information hiding.

Insecurity of information. Three participants with visual impairments were concerned about insecurity of their information, which is under-reported in prior literature. This is a security concern regarding a potential breach of confidential information [40]. While prior work has shown that people with visual impairments have privacy/security concerns about online transactions (e.g., [3]), P4 was concerned that her data might be transferred from her phone to the cloud, which could be breached. While attempting to complete one of the predefined tasks, P4 described a habit of taking photos of her credit cards so that she can enlarge the numbers to see. But she immediately deleted these photos so that they cannot be seen by someone else and would not be in her phone if the device gets lost or stolen. However, she was not sure where the pictures went. She explained: *"..like if it's still in the cloud or somewhere; it worries me."* P4 did not consider this practice as a safe thing to do, because her sensitive financial data might be transferred to and stored in the cloud, where others might gain access to and/or misuse her data. However, she did so to make herself more independent in purchasing. This highlights the trade-offs between independence and privacy/security that people with visual impairments often had to make.

5 Social Relationships and Interactions

The everyday practices of people with visual impairments often involve interactions with other people such as allies (e.g., family and friends) and even strangers. This section focuses on these interactions with an attempt to highlight the underlying nature of these relationships and interactions reflecting elements of agency, interdependence, and trust that shape their everyday experiences.

5.1 Family Relationships

Family members such as spouses, domestic partners, parents, children or siblings often serve as allies for people with visual impairments because their actions may reflect understanding, commitment, mutual trust, and shared decision making.

Spouses. We observed that marriage or domestic partnerships often involve more reliance than friendships and other familial support. Two of our participants with visual impairments (P3 and P5) are both married. For instance, P5 stated during the initial interview that he completely trusts his wife (A3-P5) and is dependent on her to assist him in a wide variety of tasks. P5 recalled an essentiality to share passwords for emails and other critical information about banking with A3-P5. While he was unconscious (resulting from an accident 4.5 years ago when he lost his vision), she needed to access his emails and bank accounts to pay bills and respond to important emails on his behalf, therefore A3-P5 also manages the information being shared between her husband and certain organizations. However, sometimes, organizational policies make it difficult for A3-P5 to help him. She mentioned during the exit interview that she is his power of attorney, which gives her the legal authority to make decisions on his behalf in all financial and legal matters. A3-P5 shared an example: *"There was one situation where somebody said they could not speak to me because their rules were they had to give the information to my husband and literally, he said 'give it to my wife and she will write it down' and he said he could not do it, and he said 'we're basically at an impasse here because basically I can't write it down, so you are going to have to give it to my wife."'* Eventually, they gave the information to her.

The organization in this example practically created inaccessible conditions. P5's interdependent relationship and practices with A3-P5 were in conflict with the organization's policies. While these organizational policies may have been designed to safeguard the security of the users' information, they failed to take an inclusive approach by making the process more accessible for people like P5, who is blind and hard of hearing. These overlapping dimensions of P5's identity might explain why it is difficult for him to write down something said over the phone. While prior work shows that people with visual impairments struggle with password management (e.g., correctly typing passwords [3]), our study presents this novel finding that organizational policies designed to protect users' privacy and security can also be challenging for people with visual impairments such as P5.

Parents and children. Most participants with visual impairments often asked their parents and/or children to assist them in different activities such as banking and transportation. For instance, P2 is blind and has bipolar disorder and a learning disability. She often relies on her mother (A2-P2) for help. During the exit interview, P2 explained an incident about finding a person through an online dating site. When she decided to meet this person, her mother offered to drive her to the meeting place. However, her mother did not let P2 get out of the car because she felt the person looked suspicious. In this case, her mother attempted to safeguard her from potential risks but P2 did not really have much control over the situation, because her mother made the judgment for her. This could raise the question of P2's abilities to engage in a relationship independently. P2's multiple disabilities and gender identity could make her particularly vulnerable in these circumstances, which might explain the trade-off her mother made in this case between P2's safety and her social life.

Prior literature suggests that people with visual impairments are concerned about their privacy when asking strangers to help but are comfortable in asking for help from a known person (e.g., [3]). However, a novel finding we observed was that privacy is an important factor when some participants with visual impairments were considering whom to ask for help even if these individuals are their own children. For instance, P4 gave a concrete example in response to a follow-up question we asked her after completion of the entire study of not asking her daughter to fill out forms that require financial information. She explained: *"If I'm filling out a camp scholarship form and my daughter is helping me and it starts asking for salary and blah, blah, blah, I don't. It's mostly because I'm in a divorce situation and I don't want her to accidentally tell her father. Yeah, my kids are pretty trustworthy but I don't trust my ex-husband."* This example highlights how P4 consciously considered potential privacy risks (leaking her salary information to her ex-husband) in mundane activities in her everyday life. While P4 trusted her children to help her, she did not want her ex-husband to know about her financial information, which may put her at risk.

5.2 Romantic/Dating Relationships

Romantic/dating relationships can be a source of allyship but might also have privacy risks in this context. For instance, P2 has a boyfriend but avoids to have any other male friends. During the exit interview, she explained: *"It's just if I were to have a guy friend, being blind, you really can't hide that on your phone. Sometimes people can do that. They can hide different things nowadays on phones. I've been told they're able to, but I just find it easier to not even be friends with guys*

at this point."

P2 viewed her phone conversations as something private and did not necessarily want others, even those who are close to her, to know about. While visual/aural eavesdropping was reported as a privacy concern in prior work (e.g., [3, 4]), P2's case was different because she was concerned about her boyfriend accessing private/personal data *stored* in her phone. P2 discussed hiding phone conversations from her boyfriend because talking to other male friends might cause misunderstandings between her and her boyfriend. While physical access to a person's phone conversations can happen to anyone, cisgender women with disabilities could be more vulnerable (e.g., in abusive domestic relationships where women are often the victims [22]).

P2 would love to be able to control the visibility of these conversations herself, but she felt the technologies are too complicated for her to learn. As we noted earlier, she also self-identified as having bipolar disorder and a learning disability, struggling with technologies. While technical features such as deleting a phone call record or a text message may allow people to hide certain social interactions on the phone, there are no technical features explicitly marked to "hide conversations on a phone." In order to achieve such goal, one would need to take a socio-technical approach, which may require a good understanding of the phone and its technical features as well as the social implications of using such features. Since P2 generally struggled with technologies, she may find those features overwhelming to learn.

5.3 Friends

Friends are also a source of allies for people with visual impairments. For instance, P1 and A1-P1 consider each other to be close friends. During the observation portion of A1-P1's second session accompanying P1, we joined them at the local mall. P1 found something to buy. At the register, there was a line and the cashier was trying to move everyone along quickly. Once P1 reached the cashier, he was prepared to pay with his card. P1 asked A1-P1 to take out his wallet and then A1-P1 identified the card to pay by himself. However, this store only accepted cash. We saw some people in the line looking impatient. Although P1-A1 did not say that he felt pressured in that situation, we observed him taking notice of the people waiting in the line. As a result, A1-P1 voluntarily stepped in, before P1 could ask, and removed cash from P1's wallet to pay the cashier and finish the purchase.

A1-P1 had complete access to his friend's wallet at this point, which in theory could pose financial and privacy risks to P1 (e.g., taking extra cash, knowing how much cash he has, remembering and even misusing his credit card information). In that moment, A1-P1 sensed social pressure (many people waiting in the line), and took control by quickly completing the transaction through cash. By enabling a quicker transaction at the potential cost of P1's financial privacy, A1-P1 prevented P1 from becoming a target of general public frustration by taking too much time to complete tasks that may seem easy for people without disabilities. The inaccessibility of the store was at odds with P1's loss of vision, which influenced his decision to ask his friend to access his wallet and assist with the payment process. However, P1 exercised his agency by consciously making the decision to ask his ally for help. He trusted A1-P1 and was interdependent on him to help perform this financial transaction.

5.4 Professional Relationships

Some of our participants with visual impairments also had allies who provided (paid) professional services (e.g., filing taxes). Moreover, they might also ask these allies for help even for tasks falling outside the responsibilities of these allies. For instance, P1 has a mobility trainer to train him with physical navigation. Since P1 is blind, he relies on the assistance of this mobility trainer to develop non-visual cues and landmarks to navigate his physical environment independently. During the observation portion of P1's first session, we observed this mobility trainer assist P1 in finding the route from his apartment to his classroom. As they started from P1's apartment, they stopped by to check his mail on the ground floor of his apartment building. P1 asked his mobility trainer to read his mail. One of the letters seemed to be from a financial institution. P1 asked the mobility trainer to open the letter, who identified it as a check and gave it to P1. We then accompanied them to the bank and a teller recognized P1 and helped him deposit the check. Later we asked P1 for any concerns about other people reading his letters, he explained: *"I am not so much concerned with someone reading my mails, because they are not reading without me telling them. I'm the one asking them, 'can you read this?"'* P1 has developed a trustworthy relationship with the trainer and felt comfortable asking him to read his mail.

There were power dynamics between P1 and the mobility trainer in the form of a professional (paid) relationship between them. Yet these dynamics were diluted by the interplay of an informal friendly relationship, on the basis of which P1 asked his mobility trainer to read his personal mail. Furthermore, by asking his mobility trainer to check his mails, P1 said he has full control over the situation, suggesting that he was exercising his agency. However, at least theoretically, there is a privacy risk for P1 that the mobility trainer could learn/misuse his sensitive information (e.g., bank account and balance). P1's action of giving consent to his mobility trainer to assist him with this task may suggest that either he is potentially aware of the risk involved or may be choosing to ignore such a risk over convenience. Brady and Bigham have discussed people with visual impairments seeking help in a computer-mediated fashion via crowdsourcing or friendsourcing (e.g., asking crowd workers or friends to fix web accessibility issues or to identify the kinds of objects in a pic-

ture) [14]. In comparison, our study shows this phenomenon in an offline, non-technology-mediated manner that could also pose privacy risks. This kind of offline scenario is a rich space for future privacy research and design.

5.5 Strangers

People with visual impairments usually do not consider strangers as allies. However, occasionally, our participants still found themselves in situations where they had to ask for help from strangers or were even approached by strangers for help. In those cases, physical safety or security might be a concern. For instance, during the initial interview, P1 described an incident where he tried to walk to a local restaurant alone. At that moment, he was approached by a group of people who offered to escort him to the restaurant. When they all reached the restaurant, this group of people asked for money in exchange for helping him and P1 paid them $10. Later when P1 told A1-P1 about this incident, he said that P1 was not really supposed to give money to people on the street.

5.6 Allies' Perspectives

Each of our ally participants also had interesting and unique perspectives about their relationships with those with visual impairments that they often interact with. A1-P1, for example, disclosed during his exit interview that he respected P1's agency and advocated not to offer help unless P1 asks him for such help. He also perceived P1 to be independent and able to manage most aspects of his everyday life very well. However A1-P1 also jumped in to assist him with tasks such as navigating large spaces. A2-P2 took into account not only her daughter's visual impairment but also her mental status, considering how her bipolar disorder and her loss of vision impact her everyday life. In response to a follow-up question we asked A2-P2 after completion of the entire study, she stated: *"I believe in complete right to privacy in all situations dealing with P2. She is an adult and my help to her is strictly for her benefit and I consider any breach of her privacy to be also a breach of trust."* Taking into account P2's multiple disabilities (including visual impairments) as well as her mental condition and gender identity, A2-P2 took privacy concerns very seriously and felt any help and action she would take would only be of her daughter's best interest. The primary priority of A3-P5 was her concern for her husband's safety in general, particularly navigating outside of the home environment. She identified key risk points and assisted him with various tasks in the home. She also felt that her husband being hard of hearing also plays a role in their daily lives.

In summary, the lessons we learned from the perspectives of allies reflect a sense of accommodation and agency. All three allies understood the limitations of our participants' visual impairments along with their multiple identities and provided assistance for them to complete their daily tasks while valuing their privacy and security. They also provided an environment of agency where allies respected our participants' autonomy instead of our visually impaired participants completely depending on their allies for complete assistance.

6 Discussion

In this section, we discuss the implications of our results. Following the recommendation of being self-reflexive as researchers [41], we start with information about our research team to contextualize our discussion that follows.

6.1 Researcher Self-Disclosure

Our research team consists of individuals across a variety of academic backgrounds and identities. We find this diversity brings strength to our research. Our team has cisgender identified men and women, an Asian American, a Caucasian American, and people from Asian countries. We understand that there are certain privileges associated with our notions of self and we benefit from the ideas of people of color (e.g., [17]). While some of us wear glasses and/or have "hidden" disabilities, they are not the same as visual impairments. Thus, our understandings of the participants might be limited. Nevertheless, we self-identify as allies in the disability community.

6.2 Everyday Privacy/Security Practices

While there is a vast body of literature on people's privacy concerns, preferences, and practices (see [23] for a comprehensive review), most empirical work in this line of research focuses on individuals, i.e., the unit of analysis is individuals making decisions about their own privacy. The few exceptions that examine the privacy management and practices of pairs or groups of people tend to focus on social media, for instance, how one user might intentionally or unintentionally disclose information of another person on social media (e.g., [29]).

A crucial element of our approach to study the everyday privacy and security practices of people with visual impairments was to pay close attention to their relationships and interactions with their allies. Therefore, our analysis focuses on not only individual-based but more importantly *group-based* privacy management (i.e. individuals with visual impairments working with their allies). In addition, we have discovered that our participants' self-notions of their disabilities, their conceptualizations of privacy, and the multiple aspects of their identities (e.g., disabilities, gender identity) influenced their privacy and security practices. We elaborate on this discussion by revisiting our two research questions.

First research question: *what are the everyday privacy/security concerns, challenges and practices of people with visual impairments in their daily lives?* Our study corroborates with prior literature that shows people with visual

impairments have various physical/offline and online privacy/security concerns such as shoulder surfing and hacking (e.g., [3,4]). Yet our study also provides novel results in terms of how our participants with visual impairments view their disabilities and how their notions of privacy affected their privacy and security practices, for instance, whether to disclose their disabilities (e.g., P3's example of selectively informing his email contacts about his low vision).

Our study also reveals understudied challenges of people with visual impairments in managing their social relationships (e.g., P2's example of meeting someone from an online dating site and her hypothetical example of hiding conversations on her phone so her boyfriend would not misunderstand). P2's attempt to hide conversations on her phone is a form of user appropriation of technologies (e.g., phones).

While user appropriation of technologies for their own purposes has been extensively discussed in the literature (e.g., [49]), we paid extra attention to the complex identities of our participants with visual impairments in understanding their everyday privacy and security practices including technology appropriations. Three participants with visual impairments also have other disabilities or significant health conditions. Some participants are older adults. One female participant was in a divorced situation and another male participant came from an African country with a very different culture. All these aspects of their identities play a role in shaping their varied experiences and privacy/security practices.

Sociologist Erving Goffman has written about disabilities being considered as a stigma by some people and the techniques that people with stigmatized identities used for information control (e.g., covering their identities) [26]. Our study investigated the social/collaborative aspect of privacy and security practices including information control. This leads to our second research question.

Second research question: *how do people with visual impairments interact with their allies? What are the privacy or security implications of such interactions?* While prior literature touched on the general phenomenon that people with visually impairments often seek help from their allies (e.g., [3, 4]), our study dove deeper into the social relationships and interactions between adults with visual impairments and their allies, drawing our attention to issues such as agency, interdependence, and trust. We found that our participants interact with their allies in various social settings and everyday activities such as physical navigation, personal finance, doing laundry, grocery shopping, managing social relationships, and using technologies. Our participants sometimes asked their professional service providers to help with tasks that were outside the scope of the service providers' responsibilities (e.g., P1 asking his mobility trainer to check his mails). While this practice might pose a privacy risk, this is understandable because participants with visual impairments have built a trustworthy relationship with their allies.

From our ally participants' perspectives, they respect the independence and privacy of their partners with visual impairments. While these allies often provided help only upon request of their partners, occasionally they acted without explicit request (e.g., P1's friend/co-worker, A1-P1 removing cash from P1's wallet to pay for P1's purchase without his request; and A2-P2 not letting P2 to leave the car to meet with the individual she met on a dating site). These occasional cases highlight the trade-off between respecting their partners' agency and protecting them from unnecessary embarrassment or privacy/security/safety risks. How to better support social interactions and co-decision-making between people with visual impairments and their allies deserves further research.

Furthermore, we observed that our participants with visual impairments were often thoughtful about when to ask whom for what kind of help. Notably, a novel finding of our study is how privacy plays an important role in the decision making of our participants with visual impairments in asking allies for help (e.g., P4's example of not asking her daughter to fill out scholarship forms that ask her salary information, which her ex-husband might then learn). More broadly, our participants with visual impairments hope to achieve more control over their own lives (a form of agency), being able to choose independence or interdependence as they deem appropriate.

6.3 Implications for Research and Design

What do these insights of people with visual impairments and their allies mean for privacy research and design?

Cooperative privacy and security.
The first key implication is that *privacy management can have an inherently cooperative dimension*. The basic assumption behind most of the existing end-user privacy tools is that privacy management is a personal/individual behavior. Therefore, existing tools are often framed as helping individuals protect their own privacy. However, as our study highlights, people with visual impairments often work closely with their allies to protect their privacy and security. By "cooperative," we intend to call attention to the aspect of mutual assistance in working together towards a common goal in protecting privacy and security. Although prior work [29, 31, 36] discusses the concept of cooperative privacy, our study offers an understudied and nuanced understanding of cooperative privacy practices, which dovetails with the idea of interdependence in the context of people with disabilities and their allies.

In recent scholarship in accessible computing, researchers have highlighted the importance of interdependence. For instance, Bennett et al. advocate interdependence as a frame for research and design of accessible technologies [8]. Traditionally, the main goal of accessible computing has been to support independence of people with disabilities (e.g., independent living). However, Bennett et al. argue that interdependence is also vital, drawing from the literature of disability studies, disability activism, and the social aspects of accessible computing [8]. They use the term interdependence to describe

mutual relations and interactions between people and their environments. Importantly, they highlight that people with disabilities and their allies help each other instead of people with disabilities being "passive recipients of assistance."

Our study results and the concept of cooperative privacy and security align well with Bennett et al.'s framework [2] of interdependence. Our participants with visual impairments and their allies value each other's strengths, differences as well as their holistic characteristics and unique needs to collectively manage their everyday privacy and security. For example, A3-P5's management of her husband's passwords and financial information, A2-P2's accounting for her daughter's multi-faceted disability identity when overseeing her credit cards, bank accounts and physical safety and A1-P1's ability to meaningfully respond to his friend's needs in terms of perceiving potential privacy risks allows each party to fully understand the true strengths and vulnerabilities of one another and use them to their own advantage to provide meaningful feedback, establish a system of trust and communicate potential dangers in relation not only to each other but the world in which they live. Furthermore, each of the allies we studied recognizes the contributions of our participants with visual impairments instead of providing care that does not fully comprehend the strengths of their care recipients. In line with Bennett et al.'s work, these simultaneous and visible relations are key for applying interdependence to cooperative privacy and security because people with disabilities and their allies must delve beyond the surface of providing care and utilize their relationships to truly assess their unique privacy and security needs and experiences.

Privacy and security mechanisms are often focused on the individual's perspective, for instance, a privacy or security warning that a user can act on. In contrast, cooperative privacy fosters interdependence, which is especially beneficial for the every-day privacy management of people with visual impairment. What would a "cooperative" warning look like? Perhaps it could have built-in support for people to seek help or get feedback from others (e.g., allies), for instance, an option on the warning to ask for help. One possible cooperative privacy design could take the form of a mobile app or a website where users with visual impairments could choose to share only with specific allies they invite to the system any information about them, such as schedules and common tasks they perform. If users felt their privacy/security is at risk, they can request help from selected allies, requesting a chat session in real-time where allies would be providing assistance as needed. Users would have full control over the disclosure of any private information that they share via the system. This is just one example of a rich yet largely untapped design space for cooperative privacy and security mechanisms. These types of designs will not only be helpful for people with visual impairments and their allies, but also computer users more generally (e.g., technically savvy users and novice users).

Prior research such as [46] has suggested that group-level analyses of privacy behavior are rare but needed, and our research provides empirical data to support such a claim and a concrete context for exploring group-level analyses. Xu conceptualizes collaborative privacy management as the collaborative strategies and practices that individuals use to protect their privacy as group members [52]. A number of collaborative privacy management tools have been proposed mostly in content sharing scenarios among users of social networking sites [1, 9, 18, 33, 50]. These solutions were usually in a scenario where a person's privacy is violated by another person's behavior, e.g., one person tagging another person in photo posted on social media. None of these mechanisms were designed to cater to people with disabilities and their allies where often people with disabilities face privacy risks and then collaborate with their allies to address those risks.

Cooperation might introduce risks. The second key implication has a critical nature: *cooperative privacy management can also introduce new privacy risks in the context of people with visual impairments.* This is especially true when sensitive information related to a person with visual impairments may be exposed to or shared with allies. For instance, when P1 asked his mobility trainer to check his mails, the mobility trainer had access to P1's mails, including financial documents such as a check from the bank. This can be a risk for cooperative privacy in alternative situations because the ally (in this case the mobility trainer) might access personal/sensitive info about people with visual impairments even though this information may be willingly shared by people with visual impairments based on their mutual trust. In theory, the mobility trainer has access to P1's sensitive information, which could be misused. Our study points to the need of designing mechanisms that facilitate these types of cooperative privacy practices while mitigating the potential privacy risks this practice might introduce. This design dimension is crucial for people with visual impairments and can be relevant for other marginalized groups such as children and older adults.

In the accessible computing field, there are a number of proposed tools to support collaboration between people with and without disabilities (e.g., [6, 12, 38, 42, 43, 51]). However, they rarely consider the privacy implications. There are also collaborative systems for people seeking and providing help. For instance, Ahmed et al. designed Suhrid, a collaborative interface for people with low literacy to seek help from helpers [2]. The system only shows the last two digits of a contact person's phone number to mitigate help seekers' concerns about their contacts' privacy [2]. Yet, we are unaware of any collaborative privacy tools that specifically support people with disabilities and their allies.

Multi-faceted and intersectional identity. Another key implication is that *when designing privacy/security mech-*

[2]Bennett et al.'s paper is relevant but not a theoretical foundation of our study because it was published after we conducted our study. The findings emerged from our study suggest the importance of interdependence.

anisms for people from marginalized groups, one needs to pay attention to the multiple and intersecting marginalized identities that these individuals might have. As seen in our study, many of our participants with visual impairments have multiple marginalized identities (e.g., having multiple disabilities), which are intersecting and thus it can be hard to pinpoint which marginalized identity led to certain experiences or challenges. For instance, P2's challenges with keeping her conversations private on her phone could be influenced by her visual impairments, bipolar disorder and learning disability. It is unclear exactly which and how many factor(s) led to these challenges. Traditionally, privacy research and designs for people with visual impairments tend to focus on a single marginalized identity (i.e., visual impairments). However, privacy designs need to consider the multi-faceted and intersectional aspects of people's marginalized identities. We believe that one practical way to do this is through focus groups and participatory action/design research. Such studies engage these users throughout the design process to learn about their identities and needs.

In addition, the concerns raised by our participants with visual impairments show limitations in current technology designs. Our finding that users with visual impairments cannot easily delete or hide personal communications or information on their devices (or at least the perceptions of such difficulty) implies the need for more accessible solutions. For instance, a device-level, authentication-required feature that hides personal communication across multiple apps such as calls, text messages, and social media posts could be quite useful. In addition, the fact that organizations, policies or systems do not consider enough the needs of people with visual impairments and their allies for handling personal information means that these limitations make life more difficult for all parties involved. Therefore, future designs can explore how to develop more effective and usable mechanisms of sharing information between users with visual impairments and their allies. Existing solutions such as shared accounts in password managers are helpful, but they would not resolve the issue encountered in P5's example. In that particular case, a technical mechanism that allows the organization to add a password directly into P5's password manager would be helpful.

Design processes are often intrinsically power-laden [28]. Arguably, designers are often in a more powerful position than users, in this case, people with visual impairments. To follow a more equitable and empowering approach, results from this study will be fed into our follow-up research where we will collaborate with people with visual impairments and their allies to develop privacy tools using a co-design process.

6.4 Limitations

Our study has two sets of limitations. The first is related to our sample. For instance, we had a small sample size, as it was difficult to recruit participants for long hours of participation. Yet, our participants include adults that vary in the spectrum of visual impairments and other diverse identities. The inclusion of allies in our study also allows for some unique relevance to the everyday experiences of participants with visual impairments. Another limitation is that our participants were only recruited in a particular metropolitan area. Similarly, our participants are middle-aged or older adults, thus we do not know much about other age groups. Therefore, these factors limit the generalizability of our results. We also note participants knew our "shadowing" and may have avoided certain behaviors during the study.

The second set of limitations relate to our analysis/interpretation. We focused on participants' own definitions of privacy and security, which made some issues such as physical navigation less relevant for privacy/security even though it was an issue discussed generally. While we tried to consider our participants' various (marginalized) identity dimensions (e.g., disabilities, gender identity) in interpreting their everyday experiences, we lacked data to do an intersectional analysis, which rooted from the lived (subordinate) experiences of Black women and women of color [17]. An intersectional analysis should examine the *interactions* of people's marginalized identity dimensions and how those interactions explain why these people are more marginalized than considering each identity dimension alone (e.g., women of color vs. women or people of color). Our study was not designed this way and we did not intentionally collect data about our participants' complex identities (e.g., social-economic status) and how they interact. Future research should embrace intersectionality more [41].

7 Conclusion

We conducted an observational study with interviews in order to gain a deeper understanding of how adults with visual impairments interact with their allies and enact privacy and security in their everyday lives. We paid special attention to our participants' perceptions of their own disabilities, their notions of privacy as well as their social practices. Our findings highlight the need of privacy tools that support cooperative privacy management practices between marginalized users and their allies while mitigating any privacy risks that such cooperation might introduce.

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Study Script

Initial interview

1. What is your age?
2. What is your self-identified gender?
3. What is your occupation?
4. Who do you live with?
5. Walk me through what an average day is like for you. (Both weekday and weekend)
6. How would you self-describe your visual abilities? How would you self-describe your disability status more broadly? (encourage them to be as specific as they feel comfortable)
    a. (If participant mentions having visual impairment or need for visual aids) How long have you had this impairment/used visual aids?

(*For ally participants*)

7. How do you know [insert name of care recipient]?
8. How long have you known [insert name of care recipient]?
9. How often do you assist [insert name of care recipient] during an average day?
10. With which tasks do you typically help [insert name of care recipient]?
11. What information about [the care recipient] do you need to provide the help?
12. What do you typically use the Internet for?
13. How often do you browse the Internet for news or general information? How often do you check your email? How often do you shop online?
14. Do you use social media? How often do you check those accounts?
15. Do you use online banking? How often do you check your accounts online?
16. Do you have a personal computer? What is the model?
    a. Take note of operating system.
    b. Is there any reason you chose that device over other options?
    c. Which browser do you use most on your personal computer?
17. Do you have a mobile phone? What is the model?
    a. Take note of operating system.
    b. Is there any reason you chose that device over other options?
    c. Which browser do you use most on your mobile phone?
18. Do you use any other Internet-connected technologies?
19. Have you ever encountered any difficulties or challenges using technologies? Could you give me a concrete example?
    a. (If prompting is needed) When was the last time you had such an experience? Please describe it.
21. Do you have any concerns using these technologies? Could you give me a concrete example?
    a. (If prompting is needed) When was the last time you had such an experience? Please describe it.
22. Do you use any accessibility features or devices on your phone and computer?
23. Do you share your devices with other people? Who?
24. When you use your mobile phone, laptop, or accessibility devices, do you use them by yourself or in the presence of others?
25. Approximately how often do you ask for help with technology from another person?

Observation

Activity Entries
Take note of the interviewee 's (work / home) environment early in the shadowing process.
For each activity, take note of the following:

1. Start/end times.
2. Where does the activity take place (which specific room)?
3. Who is in the vicinity for this activity?
4. What personal or sensitive information is relevant to completion of this activity?
5. Is a commodity device (such as a smartphone or laptop) involved? If so:
    i. What type of device?
    ii. What operating system?
6. Is an assistive technology (such as a screen reader or magnifier) involved? If so:
    i. What type of device?
    ii. Does the assistive technology fully solve the accessibility problem for this activity? If not, record the shortcomings.
7. Are other people involved? If so:
    i. What is their relationship to the participant?
    ii. Are they an ally and/or the primary point of contact for help?
    iii. Do they have a disability?
    iv. What information does the participant provide to the other person?
    v. Does the activity require other people to be involved?
    vi. Take note of any hesitation the participant expresses in seeking help or divulging information.
8. (*For ally participants*) Are they trying to help the person for which they serve as an ally?
    i. What is the person trying to do?
    ii. Did that person ask for help? If so, what sort of help are they asking for?
    iii. What help does the participant provide?
    iv. What information did the person they're helping relay to the ally?
    v. What information does the ally access in the course of helping this person (beyond what they learned from the person they're helping)?
    vi. Does the ally do anything else with the information once they have finished with helping?
9. Does the participant use an offline method for this activity when an online method is available?
10. Do any privacy challenges arise?
    i. Does the participant try to address this challenge? If so, how?
11. Do any usability challenges arise?
    i. Does the participant try to address this challenge? If so, how?
12. Do any accessibility challenges arise?
    i. Does the participant try to address this challenge? If so, how?

Additional Tasks and Scenarios
Tasks: Now I'd like to observe how you perform specific activities with your personal devices. As I mentioned before, please feel free to say no if you feel uncomfortable with any task.

1. (*If participant uses assistive technology*) Can you walk me through the features of [insert assistive technology] that are most relevant to your daily tasks?
2. (*Ask for permission*) Can you show me how you check your email on…
    i. Your desktop (or laptop)?
    ii. Do you check your email on your phone? If so, can you show me how you do it?
        a. Which device do you use more frequently for this activity?
    iii. Do you ever experience any difficulties or challenges with checking your email?
    iv. What's your strategy for remembering your email account password?
3. (*Ask for permission*) Can you show me how you check your social media accounts on…
    i. Your desktop (or laptop)?
    ii. Do you also check your social media accounts on your phone? If so, can you show me how you do that?
        a. Which device do you use more frequently for this activity?
    iii. What do you like to check on your social media accounts?
    iv. Do you ever experience any difficulties or challenges with checking these accounts?
    v. Does your strategy for remembering social media passwords differ from the way you remember your email password? If so, how?
4. (*Ask for permission*) Can you show me how you check your financial/bank accounts on…
    i. Your desktop (or laptop)?
    ii. Do you also check your financial/bank accounts on your phone? If so, can you show me how you do that?
        a. Which device do you use more frequently for this activity?
    iii. Do you ever experience any difficulties or challenges with checking these accounts?
    iv. Does your strategy for remembering financial/bank passwords differ from the way you remember your other passwords? If so, how?

Scenarios: Next, I want you to imagine yourself in each of the following scenarios and tell me what challenges or concerns may arise for you. If you've had such an experience before, describe to me the most recent time it happened.

1. You need to run some errands around town, such as buying groceries and going to the post office. (*If needed, prompt the participant to talk about how they get around town*.)
2. (*If applicable*) You schedule a pickup with Call-A-Bus.
3. You share your medical history with an assistant in the waiting room at the doctor's office.
4. You read your email at a bus stop, and several other people are waiting or passing by.
5. You type your email password into your phone in the breakroom at work.
6. You withdraw cash from an ATM.

(Only for ally participants)
Tasks: Earlier today, you mentioned that you typically help [insert name of care recipient] with [*list tasks from initial interview for which the ally provides help*]. If you don't mind, I'd like to walk through how you provide that help. As I mentioned before, please feel free to say no if you feel uncomfortable with demonstrating any of these things.

For each task in the list from the initial interview, ask the ally to demonstrate how they provide help.
Ask the following questions during each walkthrough:

1. Do you typically ask [insert name of care recipient] whether they need help in this task, or do you provide help unprompted?
2. Do you always feel prepared to help in this task? If not, describe the last time you felt unprepared to help with the task.
3. Do you have to ask [insert name of care recipient] for specific information when you complete this task? What information?
4. Is there any personal information relevant to this task that you already know? What information is that?
5. Do you ever feel uncomfortable providing help with this task? Which components of the task make you uncomfortable? Why?
6. Do you ever have trouble helping [insert name of care recipient] with this task? Please describe the specific challenges for me.
7. How do you overcome these challenges?
8. Have you ever made mistakes with this task in the past? If so, what have been the consequences?
9. Have you ever regretted providing certain help? Could you give me a concrete example?
10. Do you ever require the help of others beyond [insert name of care recipient] to complete this task?

Additionally, take note of the following:

1. Does the ally interact with the care recipient when providing help, or do they complete the entire task independent of the care recipient?
2. Do they access more information than they need for the task? Was this a mistake?

Exit Interview
(*For participants with visual impairments*)

1. Does your use of [insert assistive technology] change between the home and work/public environment? If so, why?
2. Do you ever hesitate to ask for help from your ally? If so, under what circumstances?
3. Beyond your ally, who do you trust to help you with tasks that are inconvenient?
4. Do you ever hesitate to ask for help from strangers? If so, under what circumstances?
5. Have you ever regretted asking someone for help? Or provide information to someone so that they can help you? Can you give me a concrete example?

(*For ally participants*)

6. Do you ever provide help to [insert name of care recipient] unprompted? Can you give me concrete examples?
7. Do you ever have trouble helping [insert name of care recipient]? Can you give me concrete examples?
    - How do you overcome those challenges?
8. Do you ever feel uncomfortable with the type of information you handle when providing help? Can you give me concrete examples?
9. Do you ever access or see more information from [insert name of care recipient] than the task requires? Can you give me concrete examples?

10. In what locations do you feel comfortable using your…
    i. Email accounts?
    ii. Social media accounts?
    iii. Financial accounts?
11. What does privacy mean to you?
12. What privacy concerns do you have when browsing on the Internet?
13. What privacy concerns do you have beyond Internet browsing?
14. Do you have specific privacy concerns about your mobile phone, personal computer, or work-related devices?
15. Do you ever check out online advertisements? Have you come across any advertisements that appear to be tailored to you? Can you provide a concrete example?
16. How do you currently cope with the privacy concerns or challenges you experience?
17. Do you have suggestions for solutions to these privacy challenges?

Wrap up

We really appreciate all the time you've given us. As we wrap up, let me summarize some of the key points I've learned today.

1. Create a large interpretation of your learning about the user's daily activities. The wrap-up is an opportunity to summarize what you learned about the user's experience. It is a way for you to check your high-level understanding with the user. Specifically mention the following:
    i. Computer usage
    ii. Online activities
    iii. General use of technology
    iv. Major challenges encountered during an average day
    v. Privacy attitudes, concerns, and needs
    vi. Participant suggestions for protecting individual privacy
2. Clear up any thought processes or observations that need further clarification.
3. Ask the participant to reflect on their experience with the observation, and ask whether there is anything else in terms of privacy, usability, or accessibility they would like to add.
4. Ask the participant after both sessions: **"**Was there anything that made you uncomfortable today?"
5. Ask the participant after the first session: "Is there anything I should do differently when observing you?"
6. Can the user suggest another interested person with visual impairments who would like to get involved with the study?
7. Thank the user for his/her time and give the user their compensation. Exchange contact information so that the user/researcher can ask any follow up with any questions.