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Position Paper: Exploring Security and Privacy Needs of d/Deaf Individuals

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***Abstract*—According to the World Federation of the Deaf (WFD), 70 million people around the globe are deaf. Nevertheless, d/Deaf communities remain an understudied and overlooked population in security and privacy research. In our ongoing research, we explore the security and privacy needs of d/Deaf individuals through conducting semi-structured interviews to understand d/Deaf individuals' (1) technology (non-)use, (2) the associated security, privacy, and safety implications, and (3) the interactions between d/Deaf individuals and people who are supportive of d/Deaf people when navigating S&P risks. Our observations from pilot testing show that d/Deaf individuals often have to rely on their family or friends to get access to certain information. Many information sources do not support sign language, and use complex technical terminologies that are hard for people with limited technical literacy to grasp and translate into sign language. The lack of resources may make d/Deaf individuals more vulnerable to certain scams and frauds and they resort to hiding their hearing status to protect themselves against malicious actors. Our research lays the foundation for researchers, industry practitioners, and policymakers to develop effective security and privacy tools and resources for d/Deaf communities.**

1. Introduction

According to the World Health Organization (WHO), 430 million people, equivalent to over 5% of the world's population experience disabling hearing loss [37]. The deaf community,[1] comprising 70 million individuals and having over 200 sign languages according to the World Federation of the Deaf (WFD) [36], is still an understudied population across various domains [21]. A recent surge of workshops at venues such as ASSETS, SOUPS, and EuroS&P highlights the recent growth and mutual interest in the intersection of security & privacy (S&P) and accessibility research [3]–[5].

However, much more can be done to develop a better understanding of the security and privacy needs of d/Deaf individuals. Some d/Deaf individuals rely on assistive technologies to navigate daily life that employ wireless connectivity features (e.g., hearing aids or cochlear implants). These technologies, while supporting d/Deaf individuals, also expose them to cybersecurity attacks such as eavesdropping, unauthorized access, and inference from malicious attackers [11], [18]. Additionally, certain security and privacy mechanisms, e.g. inputting particular keystrokes given by auditory instructions, remain inaccessible for d/Deaf users [7].

The lack of sign language support is a significant issue across contexts. While access to text-based information is improving over time [34], individuals who primarily use sign language for communication still encounter hurdles in their access and comprehension of information [6], [20]. This issue arises due to the prevailing emphasis on written and spoken language in a hearing society. Security and privacy-related information based on written or spoken languages would be hard to understand to non-native speakers such as individuals born deaf, especially when such information is already loaded with jargon [23]. As such, d/Deaf individuals often rely on organizations or community resources for acquiring information; however, these resources may not be available consistently and are often not well translated, inaccurate, or lack the depth of information and domain expertise [33]. Much of the information that d/Deaf individuals access is mediated through interpreters, and they feel compelled to share sensitive information with unfamiliar parties to communicate with the hearing society [13]. This phenomenon was termed 'Forced Intimacy' by disability and transformative justice activist Mia Mingus, describing the expectation to disclose very personal information to able-bodied individuals for basic access [25].

Our ongoing research explores the security and privacy needs and concerns of d/Deaf individuals across both technology-driven and non-technological scenarios

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[1] Every statistic is calculated by a certain way of understanding d/Deafness. Lowercase *deaf* is oftentimes used to refer to the audiological condition of not hearing. Uppercase *Deaf* is often used by a particular group of deaf people to empathize a sense of cultural belonging to the Deaf community [29]. In this study, we use d/Deaf to refer to people who identify as deaf, Deaf, or both and use sign language to communicate. We decided to focus on d/Deaf communities as most of our S&P implications stem from the use of sign language as a main way to communicate. Furthermore, our study design and interview protocol were predominantly shaped by discussions with members of the local d/Deaf community. The community uses both *deaf* and *Deaf* to self-identify on their website.

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via semi-structured interviews. In addition, we investigate the interactions between d/Deaf individuals and those who are supportive of d/Deaf people to observe possible security and privacy implications. This could be community members that support and regularly interact with d/Deaf community members, e.g., individuals that organize and support events for the local d/Deaf community, or friends and family members of a d/Deaf participant. Our research addresses the following research questions:

RQ1: What technology do d/Deaf individuals use, and what are common reasons for use or non-use?

RQ2: How does using technology present d/Deaf individuals with any security, privacy, or safety risks?

RQ3: How do identity-related characteristics influence d/Deaf individuals' security, privacy, and safety?

RQ4: How do d/Deaf individuals interact with their social circle and what are the security and privacy implications?

For the rest of this position paper, we describe our study's methodology, provide preliminary insights from pilot testing, and suggest directions for future work.

2. Background and Related Work

2.1. Different Models of Deafness

There are different models of deafness, such as the medical [31], social [28], and cultural models [29], [30]. The medical model views deafness as a medical condition or disability that needs to be 'cured' for the benefit of the individual and society by using speech therapy, auditory training, or cochlear implants. In the social model, deaf individuals are constructed as having an impairment. However, the primary issues is not in the hearing loss but the barriers that are created by society, such as a lack of sign language support, interpreters, and discrimination. In the cultural model, deafness is seen as its own culture with its own practices, beliefs, and native language. Sign language has its own unique grammar and vocabulary [35] and plays a major role in their everyday lives. Our research follows the social and cultural model of deafness. Hence, our focus lies on individuals who are involved in d/Deaf communities to a certain degree, not including older adults experiencing hearing loss in later life.

2.2. Security, Privacy, and Technology Use in d/Deaf Communities

Several studies have investigated technology use among d/Deaf individuals, finding that they oftentimes use internet-based everyday technology like smartphones, personal computers, and a variety of assistive technologies in the context of home, work, and school [17], [22]. Valentine et al. investigate the role and implications of information communication technologies on the Deaf community, showing how the internet contributes to d/Deaf communities building while introducing unanticipated effects [34]. Cao et al. analyzed TikTok videos authored by individuals who are deaf or hard-of-hearing[2] (DHH), finding issues related to low-quality or absent captions and voice features; while sharing DHH-related content can help raise awareness and advocates for the rights of DHH individuals, it can also lead to assaulting comments and harassment from online communities [10]. Zhu et al. explores practices of self-presentation and disability disclosure in context of online dating and found that DHH individuals hesitate to reveal their hearing status while actively revealing their relationship issues in regard to hybrid-hearing relationships; they face communication barriers, a lack of understanding, overprotection, and neglect of their independence [38].

By comparison, there has been a lack of literature on security and privacy contexts involving d/Deaf communities. Prior work identified a gap between deaf and hearing individuals in terms of self-efficacy, security knowledge, and security practices due to a lack of sign language support and accessible education sources; d/Deaf individuals utilize their support network to address security concerns, implement security features, and even support other d/Deaf people [26]. Several studies have touched upon security and privacy challenges, risks, and concerns that d/Deaf individuals have when sharing sign language video content [19], navigating authentication [14] when accessing customer service [8], or using mobile health apps [16]. However, security and privacy are often mentioned in passing and as a small part of the broader findings in these studies. Other technical security research has identified plausible cybersecurity attacks on cochlear implants [11] and hearing aids [18], emphasizing that these assistive devices are not designed in ways that prioritize security. We complement and expand on prior work by exploring certain scams or frauds that d/Deaf individuals may encounter. Our study further delves into the interaction between d/Deaf individuals and those who are supportive of them to shed light on how they seek security and privacy advice and how identity-related concerns can impact d/Deaf individuals' security and privacy practices and behaviors.

3. Methodology Overview

3.1. Protocol and Community Engagement

We developed an initial interview protocol based on the research questions, which were informed by the gaps identified during examination of previous work on security, privacy, and technology use of d/Deaf individuals. Our protocol consisted of five main sections: (1) Demographics and background, (2) Technology (non)-use, (3) S&P scenarios (scams and frauds, support and advice, disability disclosure, and interactions with third parties), and (4) S&P concerns when using assistive technologies.

As a starting point, the lead author visited a sheltered workshop[3] that accommodates members who are

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[2] Hard-of-hearing refers to individuals with mild to severe hearing loss, but not total hearing loss [37].

[3] A sheltered workshop describes a model of vocational rehabilitation for severely disabled people, who are not, not yet, or not yet again able to work on the open labor market. [1]

deafblind,[4] d/Deaf, and hard-of-hearing. Our purpose was to better understand the disability community, ensure that our research goals align with the community's interests, and seek initial feedback and guidance for our research design on aspects such as feasibility, ethical concerns, compensation, and recruitment sources. We further engaged in informal interviews with three hard-of-hearing members and piloted our initial interview protocol with two deafblind members to gather preliminary feedback. Based on their feedback, we further improved the phrasing and language of our interview questions.

Throughout the last few months, the lead author participated in various events to build trust and forge relationships with the local d/Deaf community in Herne, Germany. These events include weekly sign language classes, meetups, game nights, church events, and volunteering in a donation hosted by the community. The interview protocol was pilot-tested with one d/Deaf member of this local community. To iteratively improve the interview protocol, we further involved several members of this community as well as three experts in sign language and/or d/Deaf studies to elicit their feedback and make adjustments accordingly.

3.2. Data Collection and Analysis

For our full study, we will conduct semi-structured interviews to investigate the security and privacy needs of d/Deaf individuals. We will recruit participants who self-identify as d/Deaf and people who are supportive of the d/Deaf community. Participants will be recruited from the researchers' personal contacts and a local sign language community in Germany. Participants will also be recruited through snowball sampling, whereby participants may recommend others who qualify for this study.

To be eligible for the study, participants have to be at least 18 years old and able to communicate in German, German Sign Language (DGS), or spoken English.[5] For data analysis, we will use open coding to qualitatively analyze our data [32]. The translation of the transcript and quotes from DGS into written German language will be double-checked by the professional sign language interpreter, participant, or a trusted community member. All quotes in written German language will be translated to English written language by the lead author and double-checked by other German-speaking co-authors.

3.3. Accessibility Considerations and Ethics

This study was approved by the Ethics Review Board (ERB) at Saarland University. In addition, we follow ethical practices for conducting security research with at-risk populations [9] and d/Deaf communities [12], [24], detailed as below.

We have closely engaged with the d/Deaf community throughout the research process. We actively tried to recruit d/Deaf community members as part of our research team. Most of the individuals we managed to get in contact with were happy to review and provide feedback on our research, but did not have the capacity to get involved formally. Several members of the local d/Deaf community reviewed and approved our research design, consent form, and interview protocol.

For the full study, all interviews with d/Deaf individuals will be conducted in sign language to support communication with participants. The interviews will be mediated by a professional sign language interpreter or an individual recommended by the participant. Prior to the interview, we will obtain the participant's consent of the study purpose, procedure, and potential risks. The whole consent process will be conducted in sign language and conveyed in a dialogic fashion to encourage Q&A and allow participants to make informed decisions. We will also ask for consent before audio- or video recording and will offer to take notes if participants are not comfortable being recorded. During the interview, all participants are allowed to skip questions they do not feel comfortable answering and can withdraw from the research study at any time. We will redact any personally identifying information to protect our participants' privacy. All recordings will be deleted after our research is published. Each participant will have the option to receive 25€ at the end of the interview. Participants can decline the compensation and decide to participate voluntarily. We decided on the compensation amount based on the average hourly wage in Germany and confirmed the amount with the local d/Deaf community and pilot participant.

3.4. Positionality statement

We recognize that our personal experiences, identity, and beliefs influence and shape the research we conduct. This positionality statement outlines our researchers' identities and describes how they shape our research process and choices [15]. Among our team of five researchers, four have academic training in security and privacy. One researcher has done professional accessibility work. One researcher has academic training in accessibility research and has previously conducted research with d/Deaf communities in China. As a team, we bring together expertise in security, privacy, and accessibility and exchange knowledge across disciplines, while applying our perspectives to interpret findings and form the narrative. As a limitation, our research team consists of only hearing researchers raised in hearing culture. Nevertheless, two researchers are learning sign language and have family members/friends who are d/Deaf. This gives us a better understanding of the d/Deaf communities and culture, helping us interact with d/Deaf individuals in more respectful and responsible ways.

4. Preliminary Results

We present preliminary observations from the lead author's visit to the sheltered workshop and a pilot interview with a d/Deaf participant from a local d/Deaf community. The sheltered workshop visit included informal interviews

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[4] Deafblind refers to individuals with combined hearing and vision loss. Deafblind individuals can choose to communicate in a number of ways, including spoken languages, sign languages, tactile sign languages [27], or Lorm alphabet [2].

[5] We did not include sign languages of English-speaking countries since none of our d/Deaf participants communicate in any sign language from an English-speaking country and it would be challenging to find a suitable interpreter in Germany.

with three hard-of-hearing members and two deafblind individuals. Some of these individuals also had cognitive disabilities.

Our observations from the sheltered workshop visit show that the majority of participants utilize various technologies, including hearing aids, cochlear implants, mobile phones, personal computers, and specialized keyboards/screen readers for computer navigation, along with smart speakers. However, there is a lack of awareness among them regarding technologies commonly used by d/Deaf communities or are emerging topics in (accessibility) research, such as relay services or facial anonymization tools. Interestingly, the concepts of security and privacy were not well-understood or of significant interest to the majority of these participants: some were not familiar with these concepts; others were unconcerned about potential attacks on cochlear implants, viewing such threats as unlikely. We also noticed that some of our initial questions and probes related to negative experiences with technology or inquiries about personal identity should be approached with caution, as they can make participants feel uncomfortable, evoke negative experiences, or promote pigeonhole thinking. We will not include data collected at the sheltered workshop for our full study, as these individuals did not self-identify as members of the d/Deaf community and did not use German sign language to communicate. Nonetheless, we decided to document the observations here as it is still valuable documentation of how we scoped our research and formed the final design.

From the pilot testing with one d/Deaf member from the local d/Deaf community, we learned that information access and disability disclosure might be more important S&P-related topics for d/Deaf communities. They shared that the information sources they encounter generally lack sign language support, leading to substantial reliance on family and friends to meet their information needs. Additionally, they shared hiding their hearing status in both online and offline settings to safeguard their security, privacy, and personal safety from potential malicious actors. For instance, they refrain from sharing information related to their hearing status on social media and avoid using sign language at night.

5. Future Research Agenda

We identify two key takeaways from our preliminary findings. First, information inaccessible to d/Deaf communities can pose barriers and potentially exacerbate security and privacy risks. Second, the hard-of-hearing and deafblind individuals we talked to were unaware or unconcerned about potential security and privacy risks of certain assistive technologies such as hearing aids and cochlear implants. As such, we see opportunities for future research to (1) raise awareness of security and privacy risks more effectively, and (2) identify avenues of education to promote accurate and reliable security and privacy information within d/Deaf communities.

From our visit to the sheltered workshop, we learned that many people there are living with multiple disabilities, including cognitive and mental disabilities, yet most previous studies only focus on one aspect of disability. Thus, another direction for future research could be centering the needs of people with multiple disabilities when designing, building, and evaluating technology.

When conducting security and privacy research with the local d/Deaf community, we have also encountered several lingual and cultural issues. For instance, it is difficult to translate abstract security and privacy terms and concepts for d/Deaf participants with different education and sign language literacy levels. Professional sign language interpreters are only able to help navigate these challenges partly. Building on prior work on ethical practices for security research with at-risk populations [9], future research could establish guidelines and best practices for working with d/Deaf communities specifically (and people with disabilities more broadly) to tackle the security and privacy problems they encounter.

While usability has emerged as an important consideration when designing security and privacy tools or mechanisms, accessibility has not yet received sufficient attention. Future research could analyze specific technologies for compliance with accessibility guidelines, and make efforts to design or evaluate current accessibility tools to support developers.

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