Exploring A Reporting Tool to Empower Individuals with Intellectual and Developmental Disabilities to Self-Report Abuse

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ABSTRACT

In the US, abuse of individuals with *intellectual and developmental disabilities (I/DD)* is at epidemic proportions. Further, abuse incidents of individuals with I/DD are woefully under-reported. We surveyed practitioners who help individuals with I/DD post-abuse to get a broader context on the problem. We found that abuse of individuals with I/DD was often reported by someone other than the survivor as survivors faced impediments in reporting. Consequently, *we argue for developing a mobile-computing-based reporting tool for empowering individuals with I/DD to self-report abuse.* Next, we conducted focus groups of individuals with I/DD to evaluate the tool's viability, with respect to their ability to recognize/report abuse and use mobile-computing devices. We found individuals with I/DD could recognize/report abuse well when they received appropriate training. We also found individuals with I/DD could independently use their devices though they shared access to them with family. Based on these findings, we call for several lines of accessibility research in designing an abuse self-reporting tool for individuals with I/DD.

CCS CONCEPTS

• **Human-centered computing** → **Accessibility technologies**.

KEYWORDS

Abuse, Abuse reporting, Intellectual disability, Developmental disability, Mobile computing, Safety, Security

1 INTRODUCTION

In the US, people with intellectual and developmental disabilities (I/DD)[1] experience the highest rates of total violent crime, serious violent crime, and simple assault among people with disabilities [30]. A 2018 news report by National Public Radio, based on unpublished US Department of Justice data, concluded that people with I/DD are sexually assaulted over *seven times* more often than people with no disabilities [42]. Around 49% of people with I/DD experience ten or more abuse incidents [60]. However, incidents of

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[1]Based off of the definition of the American Association of Intellectual and Developmental Disabilities, I/DD can be thought of as a set of disabilities that negatively affect the trajectory of an individual's intellectual, emotional, and/or physical development. I/DD appear in childhood and are likely to be present lifelong [2].

abuse committed against people with I/DD are woefully underreported to the appropriate authorities. For example, only 3% of all sexual abuse cases involving people with developmental disabilities are ever reported [60].

In this work we aim to help people with I/DD fight this epidemic of abuse[2] they face. We start by obtaining a broad, community-level understanding of the problem of abuse of people with I/DD and its reporting. To this end, we conducted an online survey with open-ended questions of 16 *practitioners*, who have experience in helping people with I/DD in abuse situations (e.g., sexual assault nurse examiners (SANEs) and therapists). Our aim was to answer two main *research questions*. **RQ1:** Given the diversity within the I/DD community, who within the community is vulnerable? **RQ2:** How are abuse incidents involving individuals with I/DD reported and why? We found that: (1) individuals with I/DD were vulnerable to abuse for a variety of reasons; (2) most of the time the abuse of individuals with I/DD was perpetrated by someone they know such as a caregiver or a family member; (3) survivors of abuse with I/DD seldom reported abuse themselves as most reporting was done by others such as mandated reporters[3], friends, or family; and (4) individuals with I/DD often faced barriers to reporting from abusers who manipulate survivors to dissuade them from reporting, as well as from larger societal attitudes that often discount the voices and experiences of people with I/DD.

We believe one way of addressing this problem of under-reporting is to *empower people with I/DD to self-report abuse* and leverage a technological means of doing so. In the last two decades, we have seen a near pervasive availability of *mobile computing devices* (e.g., smartphones, tablets, and wearables). We believe that such mobile computing devices can be used to build an accessible *abuse self-reporting tool* for people with I/DD. Such a reporting tool (which we conceptualize as an *app* on the mobile computing device) would help survivors of abuse directly contact the appropriate authority to report abuse without having to rely on others.

To the best of our knowledge we are the first to address this problem of designing a mobile-computing-based abuse self-reporting tool for people with I/DD. Therefore, before we delved into designing the abuse self-reporting tool we wanted to determine if it would be viable within our community of interest. This meant answering two specific *research questions*. **RQ3:** What do individuals with I/DD know about abuse and abuse reporting? **RQ4:** In what ways do individuals with I/DD use mobile computing devices, if at all?

We conducted three focus groups involving 21 *adults with I/DD* to answer these two questions. We found that our participants did not always understand what constituted abuse or where to report it on their own. However, going through abuse prevention training improved their understanding of abuse and also their confidence in recognizing and reporting it. In terms of mobile computing technology use, we found our participants were avid users of such technology, with tablets being the preferred form-factor. However,
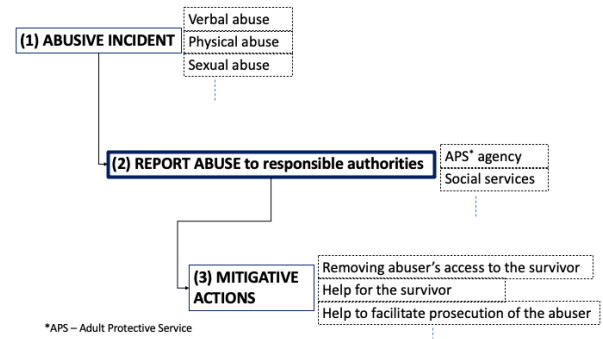
Figure 1: Illustration of a typical abuse incident reporting process

they often needed help to install and/or troubleshoot the apps on the device. Interestingly, even though most of our participants could exclusively use their devices, close family members also could log-in to these devices with the same privileges. In this paper, we document and describe the significance of these findings with respect to building an abuse self-reporting tool. Specifically, we pose several research questions in accessibility research that need to be undertaken before the reporting tool can be built.

This entire work was done in collaboration with our partners — a local I/DD self-advocacy [4] non-profit — Massachusetts Advocates Standing Strong (MASS); a local Adult Protective Services (APS) agency[5] — Massachusetts Disabled Persons Protection Commission (DPPC); and a local disability service agency[6] —Massachusetts Department of Developmental Services (DDS).

In the rest of the paper we use the terms individuals with I/DD and people with I/DD interchangeably.

1.1 Defining Abuse Reporting

To better contextualize the focus of this work it is useful to understand how the abuse reporting process works. Figure 1 describes, in broad terms, the entire process. It has three main steps: (1) the abusive incident, (2) reporting of that incident to a responsible authority (e.g., APS agency), and (3) mitigative actions by the authority to help the abuse survivor (e.g., removing the perpetrator's access to the survivor, getting medical help for the survivor, help to facilitate the criminal investigation of the abuser, etc.). In this work we are focused on the *second* element of this process, that is, reporting. We define **reporting** as making a formal complaint about the abusive incident and its context to a responsible authority. Reporting can be thought of as a discrete event focused on bringing help to the individual with I/DD.

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[2]We define *abuse* as an act or omission which results in serious physical or serious emotional injury to an individual with I/DD [37]. More specifically, we consider abuse of an individual with I/DD to be of five types: verbal/emotional abuse, physical abuse, sexual abuse, financial abuse, and neglect. This list is grounded in definitions used in psychology regarding abuse of people with disabilities [5, 41].
[3]Mandated reporters are people in specific occupations or positions that are mandated by law to report known or suspected cases of abuse. Examples of mandated reporters include physicians, therapists, counselors, etc.

[4]A civil rights group of people with I/DD that advocates for people with I/DD taking control of their own lives.
[5]APS is a general term for department(s) of various US state, county, and/or local government responsible for coordinating response to abuse of older adults and/or adults with disabilities.
[6]Department(s) within a US state, county, and/or local government responsible for providing support services to adults with disabilities to enable them to participate fully in their communities.

2 RELATED WORK

To the best of our knowledge no prior work has focused on the use of technology to empower people with I/DD in the event of abuse. The extant work at the intersection of technology and abuse can be grouped into three broad categories which we describe below. Almost all of this work focuses exclusively on people without disabilities.

Technology's role in perpetrating abuse: Much work has been done in recent years in studying abuse online. These works have included studies relating to online harassment, cyber-stalking, cyber-bullying, and harassment [9, 28, 44], with many specifically focusing on youth [4, 52] and women [15, 61]. Despite the similarities to our work, much of the literature in this area is limited to abuse in online communities with some exceptions where the threats have offline components, like rape threats [15, 61]. Further, the population surveyed is typically comprised of people *without* disabilities, though there has been some interesting work on understanding the safety needs of people with vision impairment [10]. Importantly, none of these studies involved people with I/DD.

Recent years have also seen some work focused on understanding the role of technology as a vehicle for perpetrating intimate partner violence (IPV). One of the first works documenting the role of technology in this context was [20]. The paper reported that survivors were harassed with mobile phones. In addition, they also experienced harassment (and support) via social networking sites. A relatively large scale survey of domestic violence survivors and domestic violence advocates was reported in [64]. The paper reported that mobile computing technologies were being used to isolate, punish, and humiliate domestic violence victims. Similarly, in [23] the authors performed interviews with IPV professionals and survivors to understand the role of digital technologies in perpetrating domestic violence, stalking, and surveillance of victims by abusive partners. This work was followed up with [22], where IPV survivors were interviewed to understand the specific techniques that abusers use to leverage mobile computing and cloud computing technology in the context of IPV. In [14], the authors specifically focused on the role of spyware and dual-use apps for the purpose for surveillance in an IPV context and how to help the survivors navigate such surreptitious surveillance. In addition to these works, which focused on describing and understanding the problem of the use of mobile/personal computing technologies in IPV contexts, researchers have also started working on approaches/techniques to address the issue. In [38], the authors present a three part framework for organizing technology practices and behaviors used by the survivors of IPV to deal with the abusers. In [21] the paper describes the role of trained technologists can play in helping IPV survivors understand and navigate technology issues. However, once again the focus of all this work on technology use in IPV has largely been on people without I/DD.

Technological solutions for abuse mitigation by promoting safety: When it comes to combatting abuse using technology, recent years have seen work regarding provision of peer support for harassment [43] and reducing local crime concerns [35]. Numerous smartphone-based safety apps have also become available in the various app stores. A quick search on Google Play for personal safety apps produces over 200 results. These technologies are often focused on specific communities such as women [17, 34], family/children [11, 36, 53], public transportation users [39], and people facing street/virtual harassment [19]. The safety apps on smartphones provide a variety of features, such as: sending single-touch SOS messages to specific contacts (family and friends), calling 911 with a single touch, providing location/contact of hospitals and police stations, and sounding a loud alarm. Major smartphone vendors such as Apple and Samsung have native SOS apps [32, 47] that can call emergency services. Usually they are activated by pressing a physical button on the phone several times. A recent small-scale study analyzing the efficacy of these safety apps [33] found them to be useful because they promoted collective response (getting others involved through the communication capability of the app) to a perceived threat. Similarly, wearable devices have also been developed to help with personal safety [46, 62]. These devices usually take the form of a bracelet or other jewelry that can be worn and then tapped, pressed, or shaken a specific number of times to call for help. Since these devices typically lack a high-quality user interface, they mainly provide SOS services by contacting emergency services or pre-selected contacts but do not provide services that require extensive user interaction with the device. It is unclear how commonly these devices are used and we have not found any studies analyzing their use.

Technological solutions for helping law enforcement in the event of abuse: Some technological solutions have been developed for indirectly helping older adults and people with disabilities in the event of abuse. These focus on giving law enforcement access to useful information such as: the wording of applicable laws, screening tools, resources for determining the presence of abuse, finding medical facilities, and notifying users of scams. Examples include the GANE [24] app from the state of Georgia, and the 368+ app from California [1]. These apps, though useful, are tools that aid law enforcement personnel in identifying and helping victims of abuse and neglect rather than directly assisting older adults and/or people with disabilities. Furthermore, these solutions are mostly passive and focus on providing information rather than actively helping to take action against abuse. Most importantly, these apps are not designed with people with I/DD in mind.

3 STUDY I: SURVEY: WHO WITHIN THE I/DD COMMUNITY IS VULNERABLE TO ABUSE AND HOW IS THAT ABUSE REPORTED?

We know from previous research that abuse is rampant and repeated and reporting rates are low within the I/DD community [60]. Therefore, as a first step we wanted to develop a broad understanding of abuse and its reporting with respect to people with I/DD. Specifically, we aim to answer *two broad research questions*. **RQ1:** Given the diversity within the I/DD community, who within the community is vulnerable? **RQ2:** How are abuse incidents involving individuals with I/DD reported and why? These questions help us understand the larger community-level context of abuse and its reporting as it pertains to people with I/DD. We used an online survey for this study.

ID	Gender	Speciality	Frequency of interaction with individuals with I/DD
S1	Female	Staff at a sexual assault resource agency	Weekly
S2	Female	Staff at a sexual assault resource agency	Daily
S3	Female	Therapist	Weekly
S4	Female	Physician	Daily
S5	Female	Clinical coordinator	Weekly (some daily)
S6	Female	Director at an I/DD service provider	Weekly
S7	Female	Independent sexuality consultant	Weekly
S8	Female	Advocate for people with I/DD	Daily
S9	Female	Teacher's assistant at a school with people with I/DD	Daily (school time)
S10	Female	Physician	Weekly
S11	Female	Therapist	Daily
S12	Female	Sexual Assault Nurse Examiner (SANE)	Occasionally
S13	Female	Sexual Assault Nurse Examiner (SANE) and psychiatry nurse	Often
S14	Female	Sexual Assault Nurse Examiner (SANE)	Occasionally
S15	Female	Sexual Assault Nurse Examiner (SANE)	Occasionally
S16	Female	Sexual Assault Nurse Examiner (SANE)	Occasionally (a few monthly interactions)

Table 1: Demographic information of the practitioners surveyed in our study

3.1 Survey Methods

We deployed an exploratory online survey of *practitioners* whose occupation it is to help individuals with I/DD post-abuse. Practitioners work in a variety of vocations from sexual assault nurse examiners (SANEs) to physicians and therapists and play a crucial role in helping abuse survivors with I/DD. Practitioners have a global perspective of abuse within the I/DD community and therefore can provide us the larger context regarding abuse of individuals with I/DD and the reporting of such abuse.

3.1.1 Survey design. The online survey opened with a brief introduction of our aims. We gathered information about the practitioner's role, frequency of contact with individuals with I/DD, and information about frequency and types of abuses individuals with I/DD face. We also inquired about techniques that perpetrators use, and who typically reports abuse (victim, other). We used a survey method with open ended questions for querying the practitioners. We did so because, based on our and our collaborator's experience with practitioners, we believed they would be motivated to take a detailed online survey on our topic of interest on their own time.

3.1.2 Survey participants. We recruited survey participants through our collaborator APS agency who circulated our survey to selected mailing lists of researchers in the field of I/DD abuse and health, sexual assault nurse examiners, and sexual assault response/resource agencies. We received responses from a diverse group of practitioners. Overall, 16 practitioners completed the survey, while another 16 practitioners started the survey but did not finish it. We have excluded these responses from our results. Practitioners who participated in the survey gave us detailed responses to our questions. All 16 participants had interacted with individuals with I/DD who had experienced abuse. Table 1 shows the demographic information of the practitioners whose responses are included in our analysis including how often they interact with individuals with I/DD in their work.

3.1.3 Survey analysis. The third and the fifth author coded each question for common themes and frequency of responses that met those themes. We examined the inter-coder reliability, and found high consistency between the two team members. After merging these codings into one data file, the first two authors then analyzed the data based on the frequency of themes that emerged for vulnerability of abuse, who reports abuse, and reporting prevention techniques.

3.2 Survey Findings: Individuals with I/DD are Vulnerable to Abuse for a Variety of Reasons, Survivors Seldom Report Abuse Themselves, and Face Impediments in Reporting Abuse

Our survey sought to explore abuse within the I/DD community and its reporting. Our findings from the survey are described next.

3.2.1 Individuals with I/DD are vulnerable to abuse for a variety of reasons. We first wanted to know who within the larger I/DD community is vulnerable to abuse. Most practitioners were broad in their assessment. Several stated that individuals with I/DD are vulnerable to abuse no matter their situation ($N = 6$). Moreover, they stated that the very nature of the lives of individuals with I/DD makes them vulnerable to abuse: *"None of the usual stereotypes about abuse or abusers apply. Everyone is at risk"* (S4). Others focused on specific impairments of individuals with I/DD, stating that individuals who are non-verbal ($N = 4$) are more vulnerable to abuse. This is because when abused they have difficulty expressing themselves and telling others about the abusive incident: *"...barriers to communicating abuse [and] understanding that [abuse] is wrong..."* (S11). We also received a few responses that specifically stated that individuals with I/DD who are young adults or are seniors are more vulnerable than others to abuse ($N = 3$). Finally, we had several responses that stated any individual with I/DD who relies on others due to the individual's impairments is vulnerable ($N = 3$): *"... Individuals who are more dependent on staff (i.e., living in a care facility) [are] at higher risk. I have worked with several people who have been abused by transportation providers."* (S2).

3.2.2 Abuse reporting is seldom done by survivors with I/DD. Perhaps one of our more unexpected findings was that reporting of abuse of individuals with I/DD was seldom done by survivors themselves. Most practitioners stated that reporting of abuse was usually done by someone other than the survivor ($N = 12$). The person reporting was usually someone who was told about the abuse: *"[The*

survivors] often tell another individual...who reports" (S12). Oftentimes reporting was done when someone noticed the aftermath of abuse: *"If I see a pattern of injuries that documents abuse, I describe the abuse...[that] produced the injuries"* (S4). When asked who typically reports abuse on behalf of abuse survivors with I/DD, we again got a variety of responses, including: mandated reporters (e.g., medical providers, therapists, caregivers/staff), family, friends, trusted people, and advocates for people with I/DD.

3.2.3 Abusers and societal attitudes present impediments to self-reporting of abuse of individuals with I/DD. Given that most of our participants stated that survivors of abuse who have I/DD seldom reported abuse, we next wanted to understand some of the causes for the survivors not reporting. We found that individuals with I/DD faced two types of impediments to reporting abuse. First, the abusers themselves played a significant role in preventing people with I/DD from reporting. Second, the larger societal reaction to and treatment of individuals with I/DD discouraged reporting.

In our survey we found that the abuser was typically someone with easy access to the survivor. Our practitioners pointed to several types of people whom they had identified as abusers. These included caregivers/staff ($N = 7$), known acquaintances ($N = 7$), and family members ($N = 6$). These abusers used a variety of techniques to prevent reporting of abuse. They can be categorized into three groups:

(1) Manipulating/grooming individuals with I/DD to prevent reporting: *"Getting to know a person slowly over time and crossing boundaries in a more minor way and/or verbally first to test boundaries before violation. Manipulating emotions and a client's isolation and need for connection"* (S2).

(2) Issuing threats to prevent reporting: *"If you tell, bad things will happen to you/your family; threats of death of the victim and/or victim's family if victim discloses...that victim & family will no longer be able to attend [religious] services"* (S3).

(3) Using denial of attention as leverage to prevent reporting: *"I will be your boyfriend if...or you trust me, right? Just do this one thing for me. It will be our secret. Just trust me"* (S7).

Our survey responses also pointed to additional barriers to reporting faced by people with I/DD. These emerged from larger societal attitudes that discount and downplay the voice and experience of individuals with I/DD. For instance:

(1) Blaming/shaming the survivor for the abuse: *"[The] tendency, even all these years later, is to ignore it, or worse, to punish the person who discloses abuse by restricting access to community (under the guise of safety), drugging the person (as though the shouting, crying, and raging of the victim is inappropriate) or worst of all, sending them to a class, which basically sends the message that the person's lack of education is the reason they were assaulted, effectively blaming the victim (again). Can you imagine any other... survivors being required to submit to all this? Yet it happens all the time to survivors with [I/DD]"* (S4).

(2) Survivors/people with I/DD not being believed: *"...those with disabilities are, I think, less likely to tell someone about the abuse due to the...belief they will not be believed"* (S3).

(3) Abusers not being caught, which allows them to continue their behavior: *"Anyone who has access, tendency to abuse, is*

assured they will not be caught...including attempted murder" (S3).

(4) The isolation of people with I/DD within the larger society, which allows them be victimized: *"[Abusers] manipulating emotions and a client's isolation and need for connection"* (S2).

4 EMPOWERING PEOPLE WITH I/DD TO SELF-REPORT ABUSE

We believe one way of addressing this lack of reporting by survivors with I/DD is to explicitly *empower them to self report abuse* as a way to overcome the impediments to reporting they face. This effort at empowerment will achieve two things: (1) it will give individuals with I/DD more agency in dealing with an abusive situation, and (2) it will enable more timely reporting of abuse, directly from the survivors to the authorities, without the involvement of others who may potentially question their experience. In this regard, we first examined the current abuse reporting infrastructure in the US, which provided us with an understanding of what it takes (or would take) for someone with I/DD to report abuse themselves.

4.1 Abuse Reporting Infrastructure in the US

We did an extensive manual survey of the abuse reporting infrastructure in all 50 states of the US, Washington D.C. and Puerto Rico. We found that the reporting infrastructure in the US is complicated and fragmented.

There is no one uniform and consistent method specific to reporting abuse in the US (like a 911 system for emergencies). Every state has its own approach. That being said, three methods predominate *vis a vis* abuse reporting: (1) *calling a (usually toll-free) 24/7 hotline telephone number*, (2) *calling a local telephone number or emergency response (911)*, and (3) *reporting online* [45]. Some states offer multiple ways of reporting (e.g., Florida offers both a hotline and online report [3] to their state-wide APS), while others may offer only a local number to a county APS agency [63]. That being said, the most common way of reporting abuse in the US is by making a telephone call. All 50 states, Washington D.C., and Puerto Rico provide at least some telephone call-based reporting service [45]. However, this mode of abuse reporting may exclude people who are speech-impaired or non-verbal, and those not comfortable talking about abuse. A few states (~15) do provide an online reporting service where one can go to a specific website and report abuse. However, many of the forms are lengthy and have multiple stages. Some, such as Texas even require an account to be created for abuse reporting [58]. Overall, most of these online reporting systems have been designed for use by people without disabilities such as mandated reporters. Therefore, they may be inaccessible to people with I/DD.

The receiving entity of the abuse reports is complex as well. Depending upon the state (and even county), abuse reports may be received by a variety of authorities. These include APS agencies, disability service agencies, and even law enforcement agencies (e.g., South Dakota [57]). Some states have different venues to call depending upon when the report is made. For instance, abuse reporting in Ozaukee county, Wisconsin is made to the social service

office, which is only open from 8:30am to 5pm. After business hours the office suggests calling emergency services (911)[7] [63].

This fragmentation of the reporting infrastructure makes it inherently inaccessible to individuals with I/DD. If we want to empower individuals with I/DD to report abuse, we need to make this infrastructure more accessible. One way of doing so is to develop a technological solution in the form of an **abuse self-reporting tool** that can abstract out the complexity in the reporting infrastructure that exists today, both in terms of how to report and where to report, thus enabling individuals with I/DD to effectively self-report abuse.

4.2 A Mobile Computing Device-based Abuse Self-Reporting Tool

In the last two decades, we have seen a near pervasive availability of *mobile computing devices* (e.g., smartphones, tablets, and wearables). *We believe that these mobile computing devices can be leveraged to build an effective abuse self-reporting tool (as an app) for people with I/DD.* Such a tool could help overcome some of the infrastructure complexity of reporting that exists today. In addition to supporting existing reporting methods, the reporting tool can be designed to be accessible and cater to the abilities of the individuals with I/DD in creating and filing a report. The abuse self-reporting tool could directly submit a *digital report* to the appropriate authority (e.g., APS agency) on behalf of the survivor. The digital report would reduce the need for individuals with I/DD to speak about their abuse with others and avoid some of the problems of not being believed by others that suppress reporting today. *Note that we do not claim a reporting tool will solve all problems with abuse reporting when it comes to individuals with I/DD.* However, the availability of the reporting tool will *diversify the options for reporting abuse*, which we believe will have a positive impact with respect to addressing the abuse epidemic within the community of people with I/DD.

Building an accessible reporting tool for individuals with I/DD is a complex and heretofore under explored problem. Therefore, before we delved into designing the reporting tool we conducted a study to understand the viability of the reporting tool by understanding the eventual users of the abuse self-reporting tool (individuals with I/DD) in more detail. Specifically we focused on their understanding of abuse, abuse reporting, and their use of mobile computing devices. In order to keep our attention on the broader issues surrounding the reporting tool we made *two simplifying assumptions*. (1) We assume to know what the report will contain and how to seamlessly get the information required from the individual with I/DD and their mobile computing device to the responding agency. (2) We assume to know which agency to send the digital report to. We made these assumptions because, given the diversity of the reporting infrastructure in the US, any reporting tool has to be localized to the region where it is deployed.

5 STUDY II: FOCUS GROUP: WHAT IS THE VIABILITY OF THE ABUSE SELF-REPORTING TOOL?

We wanted to build an abuse self-reporting tool for individuals with I/DD to use. To do so, we needed to understand the viability of such a tool given our community of interest. Consequently, we aimed to answer *two research questions*. **RQ3:** What do individuals with I/DD know about abuse and its reporting? **RQ4:** In what ways do people with I/DD use mobile computing devices? We asked these two questions because, if individuals with I/DD were not able to discern what constituted abuse or knew that it needed to be reported then it would be difficult to enable self-reporting as we envision it. Similarly, if individuals with I/DD did not have access to mobile computing devices in a meaningful manner then we cannot use the platform to build our reporting tool. We used focus groups in this study.

5.1 Focus Group Methods

This study consisted of focus groups with individuals with I/DD. Below we first provide details of the study methods and participants followed by a discussion of the interesting results obtained.
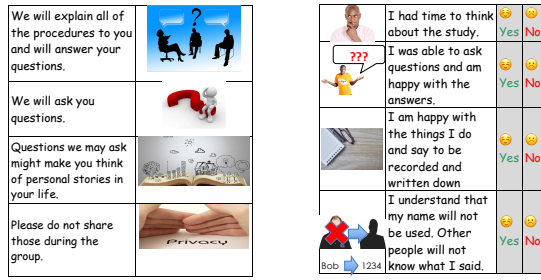
5.1.1 Focus group design. Overall, taking inspiration from [29], we approached the focus groups from the perspective that people with I/DD can speak for themselves. Our aim was to simply facilitate this process. We conducted a total of three focus groups, involving a total of 21 individuals with I/DD. In each of our three focus groups, the participants were greeted and given a brief introduction of the purpose of the focus group, the format of questions, and the duration of the study. We then spent a considerable amount of time reviewing the informed consent process. Each focus group lasted approximately 60-75 minutes.

In order to ensure our participants understood what they were consenting to, the 6th, 7th, 8th, and 9th authors of this paper created two documents to explain the informed consent form: (1) a guide and (2) a checklist. The guide provided an overview of the study and what to expect from the focus group. The checklist was a similar and related document but was written as a set of questions that the participants answered to ensure they understood the information presented in the guide. The 6th, 7th, and 8th authors of the paper are individuals with I/DD who are self-advocates who regularly run abuse prevention training workshops. The 9th author, who is neurotypical, helped and coordinated with the creation of the guide and checklist.

The informed consent form, guide and checklist were made available to the participants before the focus group, and we also went through both these documents during the focus group before the participants signed the actual informed consent document. Figures 2 (a) and (b) show excerpts of the informed consent guide and checklist, respectively. Both documents were pictorial in nature and broke down the informed consent process into easy to understand steps. To provide context to the images, supporting text was included.

Once informed consent was discussed, the participants signed the actual informed consent document. Some participants under guardianship gave a verbal assent and their guardians' signatures

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[7]Note that 911 not always the best place to call for reporting abuse. The 911 emergency system in the US triggers a medical or law enforcement response. Many allegations of abuse are not emergencies and require a response from social or adult protective services to provide appropriate support to the survivor. The 911 system is not set up to provide such services or funnel abuse related calls to the right authorities.

(a) Informed Consent Guide (Excerpt)

(b) Informed Consent Checklist (Excerpt)

Figure 2: Excerpts from the informed consent guide and checklist used prior to the signing of the informed consent document at the focus groups

ID	Gender	Age	Disabilities
P1	Male	20s	Autism
P2	Male	20s	Autism
P3	Male	20s	Autism
P4	Female	20s	Autism, vision impairment
P5	Male	20s	Autism
P6	Male	28	I/DD, mild motor impairment
P7	Male	37	Autism
P8	Female	50	I/DD
P9	Female	40	I/DD, vision impairment
P10	Male	45	Cerebral palsy, motor, speech impairment
P11	Male	50	I/DD
P12	Female	60	I/DD
P13	Male	33	Autism
P14	Female	30	Down syndrome, speech impairment
P15	Female	30	Down syndrome, speech impairment
P16	Female	50	I/DD
P17	Female	29	Oppositional defiant disorder
P18	Female	27	Global development delay
P19	Male	35	Down syndrome
P20	Female	30	I/DD
P21	Male	32	Fragile X syndrome

Table 2: Demographic information of the focus group participants in our study

were obtained post-facto. All participants were compensated for participating in the study. Finally, all documents used for this study were approved by our university and other relevant ethics boards.

5.1.2 Focus group participants. Given the sensitive nature of the work we had several discussions with our partners about who should participate in our focus groups. There was a choice between interviewing people with I/DD who identified themselves as being abuse survivors, or simply interviewing individuals with I/DD without having knowledge of whether they had been abused previously. Between the two choices, for ethical reasons we decided to recruit a general population of individuals with I/DD who had *not disclosed* being abused. We were concerned that if we interviewed people who had disclosed prior abuse, the questions might re-traumatize the participants. All our project partners (namely, MASS, DPPC, and DDS who are the stakeholders in the I/DD community in our region) agreed with this decision.

Note that just because our focus group participants had not disclosed prior abuse does not mean that they had not experienced prior abuse. It just meant that they have not reported it. Further, we wanted people to feel safe and comfortable in the focus group environment. Therefore, we gave explicit instructions that participants should not disclose abuse to us during the focus groups as we would have to report it. This is because we wanted to preserve the agency of the individual with I/DD to determine when to report any abusive incident they may have experienced in the past. Moreover, such a disclosure could be triggering to other participants as well as the person making the disclosure. In order to mitigate any potential negative consequences of our questions regarding abuse, we had a counselor present in all our focus groups to talk to any participant who might be potentially triggered. During our three focus groups, none of the participants disclosed abuse or stated that they felt triggered.

5.1.3 Participant recruitment. The participants in our focus groups were recruited through our partner self-advocacy group. All focus

group participants attended day habilitation programs. The aforementioned authors (6th, 7th, 8th, and 9th) created custom flyers for the project that were easy to understand for people with I/DD and placed them in various day programs and day habilitation locations around our region. Inspired by [55], we recruited focus group participants based on a broad definition of I/DD. The idea was to not focus on a specific medical diagnosis but rather focus on participants' observed capabilities. Consequently, we recruited people with a variety of impairments that constitute I/DD such as autism, Down syndrome, cerebral palsy, and global developmental delay. The profiles of our focus group participants are listed in Table 2. Several of the focus group participants did not want to reveal their exact disabilities. Therefore, for such participants we listed their disability as I/DD. Others did not want to reveal their exact age but gave an age range instead. Further, many of the focus group participants had impairments of vision, motor, or speech, in addition to I/DD.

5.1.4 Focus group analysis. The responses given by our focus group participants were audio-recorded as well as included in field notes from the first five authors. Subsequently, all the field notes were consolidated into a single combined response document for each focus group. The results of the focus group were discussed in team meetings during which the significance of the results was identified. The first author then listened to all three focus groups audio recordings again and transcribed the responses relating to knowledge of abuse, reporting and use of mobile computing devices. The first author then organized the transcribed elements into thematic categories and subcategories which are presented in Sections 5.2 and 5.3.

5.2 Focus Group Findings: Recognizing Abuse and Knowledge of Reporting

We first asked the focus group participants about their understanding of abuse and how to report it. Our findings are outlined below.

5.2.1 Abuse prevention training can help with building confidence in recognizing abuse. Abuse can often be subtle and not easy to discern. In this context, we wanted to know to what extent people with I/DD understand abuse. For our focus groups, the response to this question varied depending upon the participant's prior exposure to abuse-related topics in a formal setting such as an abuse prevention training workshop.

About a quarter of the focus group participants had *not* formally attended an abuse prevention and education training ($N = 5$). In this sub-group, the participants' responses to questions about abuse were generally short, less precise, and somewhat varied: *"It can be hurtful" (P1)*. When probed about various types of abuse, four of the five participants could recount only two or three types of abuse (with sexual, verbal, and physical being the most common responses). The remaining participant was less sure about their ability to distinguish abuse: *"I cannot distinguish between abuse and when two people are palling around"* (P5).

The rest of the focus group participants ($N = 16$) had attended an abuse prevention and education training at least once. Some attended regular refreshers of abuse prevention training in their day habilitation program ($N = 5$). In this sub-group, most ($N = 10$) could name all five types of abuse, with some participants showing considerable confidence in their response. That being said more than a third of the participants who had attended abuse training before ($N = 6$) were still not sure about their ability to recognize all five types of abuse.

5.2.2 Knowing where/how to report abuse improved considerably post abuse prevention training. Once an abusive situation is identified, it needs to be reported. We asked our focus group participants if they knew where to report abuse. Once again, the response to this question largely varied depending upon the participant's prior exposure to abuse-related topics in a formal setting. The abuse prevention and education training in the state where these participants were from (i.e., Massachusetts) teaches people with I/DD a variety of alternatives to make their abuse known. These include: (1) reaching out to a trusted person or a mandated reporter who then reports to the state's APS agency, (2) calling the police who then involve the state's APS agency, or (3) reporting directly to the state's 24/7 APS hotline.

For the subset of the focus group participants who had not attended abuse prevention and education training ($N = 5$), the most common response for where to report abuse was ($N = 3$) *"911"*. The other two were not sure. The reason given was that calling 911 is easier to remember and use compared to calling other numbers such as a hotline: *"I know there is a number, but I don't know what it is, so I will go with 911...it's faster" (P4)*.

In the other sub-group, which had attended any abuse prevention and education workshop ($N = 16$), the responses varied but were consistent with what was taught to them. Our participants' responses for where abuse should be reported included the state APS agency, police, caregivers or staff, and even a local private non-profit organization responsible for providing protection and advocacy for people with disabilities.

5.3 Focus Group Findings: Mobile Computing Device Use for an Abuse Self-Reporting Tool

To reiterate, our aim is to leverage mobile computing devices for reporting abuse. In this regard, it is important to understand how people with I/DD use mobile computing devices. The next set of findings therefore focuses on how people with I/DD use their mobile computing devices and whether an abuse self-reporting tool targeted at individuals with I/DD would be acceptable to the community.

5.3.1 Tablets are the preferred form of mobile computing device. A 2016 survey on the use of smartphones and tablets by people with disabilities [40] found that people with cognitive disabilities had increasingly adopted smartphones and tablets, with about 70% using smartphones and 50% using tablets. We found a similar trend with our participants, who used several mobile computing devices. These included smartphones ($N = 16$), tablets ($N = 16$), computers/laptops ($N = 16$), wearables ($N = 6$), and feature phones ($N = 5$). We had expected that smartphones would be the most frequently used device among the participants. However, we found that more participants ($N = 12$) used tablets daily and preferred using them to other types of mobile computing devices such as smartphones ($N = 9$), laptops ($N = 7$), and wearables ($N = 6$). One of the main reasons that emerged regarding the popularity of tablets was because of their form factor: *"I cannot see well, so I cannot use it [smartphone]"* (P4).

5.3.2 Installing and/or troubleshooting apps on mobile computing devices is not common, even though using an app is. Since the app ecosystem plays a big role in mobile computing devices, we asked the participants about their app use, including their ability to install, delete, and troubleshoot them. We found that the focus group participants were avid users of apps with games ($N = 8$), texting/chatting ($N = 7$), social media ($N = 6$), music ($N = 6$) and streaming ($N = 4$) being the most common. Though our participants could use an installed app and often did, questions about installing and troubleshooting apps elicited more varied responses. In terms of installing apps on their devices, about half of the participants ($N = 12$) stated that they could install apps on their own. The remaining participants ($N = 9$) stated that they needed help from others (e.g., family) to install apps. With respect to being able to troubleshoot problems with an app we found that slightly more than a third of the focus group participants ($N = 8$) could troubleshoot problems themselves. The rest stated that they solicited help from others, most commonly from parents/family members, or they simply stopped using the app.

5.3.3 Access to mobile computing devices is often shared with close family members. Next, we asked our focus group participants whether they had exclusive access to their mobile computing devices. We asked this question because we believe being exclusively able to use one's mobile computing devices would ease the ability of an individual with I/DD to self-report abuse without interference. We define access to one's mobile computing devices based on three criteria: (1) whether a person exclusively used their devices or shared the physical devices with others on a regular basis, (2) whether

they used authentication to ensure others cannot log-in into their computing devices, and (3) whether someone who exclusively used their physical devices shared their authentication credentials with others (thus allowing others to potentially log in to the device).

In terms of sharing/exclusive use of devices, we found that more than half of the focus group participants ($N = 11$) were the sole users of all their devices. The rest ($N = 10$) shared at least one of their devices. Of the participants who used shared device(s), the device shared most often were computers/laptops ($N = 7$). These computers/laptops were home computers used by everyone in the family/household. Very few focus group participants ($N = 3$) stated that they shared their tablet or smartphone devices with others. However, such sharing was usually rare, temporary, and only done with close family members.

With respect to authentication use, an overwhelming number of the focus group participants ($N = 19$) used authentication on at least some of their devices. Passwords and PINs were the most common form of authentication. Laptops/computers used by the focus group participants were always password-protected. Tablets and smartphones were protected using either PINs or biometrics, with PINs being the most common form of authentication ($N = 18$). Only three of the focus group participants stated that they used biometrics, two of them with their smartphone and one with their tablet. One of these used facial recognition while the other two used fingerprint. Only one participant used biometrics exclusively as their authentication mechanism.

As passwords/PINs were the predominant form of authentication, we asked the focus group participants if they shared their passwords with others. In all our focus groups, we found that passwords/PINs were always shared with a family member. Therefore, everyone in the focus group, even those who were sole users of their mobile connected devices, had someone from their close family who had access to their device as well.

5.3.4 The idea of an abuse self-reporting tool is appealing. Finally, we asked the focus group participants about the potential of a mobile computing device-based abuse self-reporting tool for people with I/DD. Most of the focus group participants ($N = 16$) supported the idea of having a new reporting tool that used mobile computing devices. Some wanted the reporting tool to have anonymous reporting to avoid repercussions from the abuser: *"...anonymous so that there is no backlash, in case the spouse of a friend is the abuser" (P20).* P21 wanted the reporting tool to *"both educate and report abuse".* Of the remaining participants, two expressed some interest but did not elaborate, and two other focus group participants had stepped out and therefore were not able to answer the question.

6 DESIGN OF AN ABUSE SELF-REPORTING TOOL IS A NASCENT RESEARCH AREA THAT NEEDS FURTHER EXPLORATION

Based on the responses from our focus group, we can see that an abuse self-reporting tool is viable for individuals with I/DD, if designed appropriately. Also our participants with I/DD expressed an interest in the abuse self-reporting tool. From the literature review in Section 2, it can be seen that abuse self-reporting for individuals with I/DD is an under-explored area of research in HCI. The

closest related research has been the recent focus on the role of technology in preserving physical safety. However, personal safety research has largely focused on visually impaired [10] and transgender people [48]. Some preliminary research has also explored the personal safety app ecosystem [33], but the focus was on the general population and not on anyone with disabilities. As stated in [10], researchers in HCI have also been looking into studying societal power imbalances with work on applying feminist [6] and intersectional theory [49] to HCI, which has led to the development of very useful tools safety tools [19]. However, these have not focused on individuals with I/DD. A survey of HCI literature in the last 15 years found zero pertinent results for searches using combinations of themes central to this paper such as "intellectual disabilities", "I/DD", "safety", "abuse", and "abuse reporting". Consequently, based on the responses from our focus group, we outline some of the research opportunities for designing an abuse self-reporting tool for people with I/DD.

6.1 Opportunity: Communicating the Details of Abuse and any Resulting Injury with the Reporting Tool

Since the purpose of the focus groups was to evaluate the larger context of the reporting tool's deployment, we assumed that we know what the reporting tool would look like. However, going forward, we would have to explicitly design the reporting tool so that it makes the process of sending a digital abuse report to the authorities (e.g., APS agency) easy for the reporter (i.e, survivor with I/DD) to use. Typically reporting of abuse requires giving a variety of information to the responsible agency, which then coordinates mitigative actions. For instance, at our collaborator APS agency the following types of information are collected when abuse is reported: (1) demographic information of the survivor, (2) details of the abuse incident, (3) demographic information of the perpetrator, (4) any relevant guardianship information about the survivor, if applicable, (5) location of the incident, (6) type of injuries, and (7) whether the reporter believes the person remains at risk. Agencies in other states have similar requirements [3] [57].

Some of the information such as (#1) and (#4) can be pre-deployed within the tool at installation time, others such as (#5) can perhaps be generated automatically (e.g., using in-built device GPS). One very interesting possibility in this regard is the use of techniques from augmented and alternative communication (AAC) technologies. AAC technologies are typically used to enhance the communication capabilities of individuals with disabilities (especially with speech impairment). They offer a platform to convey one's needs and supplement their vocabulary [26]. In recent years, AAC technologies have been investigated for people with I/DD to be used in a variety of contexts including enhancing communication [31, 50, 56, 59], building education tools [13, 65] and understanding the larger design of AAC tools for people with I/DD [8, 16, 51]. Of particular interest is the recent work done on explaining clinical symptoms to physicians by people with I/DD [25–27]. Though not related to abuse, these works focus on helping individuals with I/DD describe complex situations about themselves to a third person (a physician). Methods and results from this research can be a starting point for abuse reporting using AACs as well. Interestingly,

such technologies can not only be used to describe abuse in the course of reporting abuse, but also to enhance the communication of survivors during any subsequent medical, social, or forensic interviews. Further, such a communication tool can be useful to a variety of populations, not just individuals with I/DD. For example, the broader disability community can also use it for describing abuse and sharing their experience with others.

Some of the main open research questions in this area are:

- What is the level of detail that is required by the receiving agency in abuse reports to make the report actionable?
- How should the user interface of the reporting tool be designed to support the use of AAC-technologies in abuse reporting?
- How can AAC-technologies be used for medical, social, and forensic interviews that follow a typical abuse report?

6.2 Opportunity: Securing the Reporting Tool from Abusers

As the reporting tool becomes prevalent, abusers might augment their tactics (e.g., grooming, threats, etc.) to directly prevent individuals from using the tool. This is a difficult challenge, especially if the abuser is someone who is a close family member with access to the devices of someone with I/DD. A wearable solution might be a better option in such situations, provided the individual with I/DD can always wear it. In either case, the exact countermeasures should involve both technical and non-technical measures (e.g., having a pre-determined safety plan and adhering to it).

To the best of our knowledge, no prior work has designed a system for people with I/DD to prevent tampering by abusers. The closest literature to this issue is Intimate Partner Violence (IPV) research, which is included in our literature review (in Section 2). This work addresses abuse when a close partner has intimate access to the victim. While this work is close to the threat model for a reporting tool, it does not investigate specific needs of people with I/DD.

From a security standpoint, the aspects to investigate for HCI researchers are how to design the reporting tool ensuring its *availability* for individuals with I/DD. For instance, authentication could potentially be used to limit the abuser's ability to prevent reporting. However, it may not be sufficient because of the underlying threat model. The abusers could manipulate (coerce, cajole, and bully) the individual with I/DD to reveal authentication credentials. If the abuser is a close family member, then they may already have access to authentication credentials. Other issues to consider include abusers affecting the operation of the reporting tool, the device it is on, and internet connectivity to prevent reporting. In such situations the individual with I/DD cannot use their reporting tool (if needed). Further, they may be isolated from others who could help. To overcome such problems the reporting tool could be designed to leverage the typical *interdependence* [7] of individuals with I/DD with others and involve trusted third-parties (e.g., friends, co-workers, human rights officers at the day habilitation centers) to assist them.

The main open research questions in this area include:

- How can authentication solutions for mobile computing devices be designed to prevent abusers from affecting the reporting tool?
- How can designers leverage the various forms of interdependence in the lifestyles of individuals with I/DD to help them if their reporting tool is made unavailable?
- How can designers balance the tradeoff between involving third parties and maintaining the privacy of the individual with I/DD in the course of securing the availability of the reporting tool?

6.3 Opportunity: Exploring How to Facilitate Recognizing Abuse

In our focus groups we found that individuals with I/DD may have an incomplete understanding of abuse unless they attend abuse prevention training. Therefore, any reporting tool should also be accompanied by a separate or integrated *learning tool* for teaching individuals with I/DD about various types of abuse. Such a learning tool should be designed to be used independently or in an educational setting (e.g., abuse prevention trainings) to ensure people with I/DD understand and remember the various types of abuse they may encounter. We asked our focus group participants if a learning tool should be developed to teach abuse prevention. Most focus group participants (N = 15) agreed, with a smartphone and tablet-based app as the learning tool being the preferred option (N = 9).

We believe the learning tool should cover a variety of topics including: various forms of abuse, sexual health and relationships, assertiveness skills, and learning about social cues. However, simply having the tool will not be sufficient; the learning tool has to be engaging. How to make the learning tool engaging, without diminishing the seriousness of the topic, is something that needs to be considered carefully, and presents interesting research opportunities for designers. Importantly, we are not advocating for a complete abuse training to be done via an app on a mobile computing device. Rather, we are interested in providing a means for refreshing concepts from time to time, independently if possible, after attending an abuse prevention training workshop. Hence, the content shown to the individuals with I/DD has to mirror the training workshop itself. That being said, the question remains whether these can be done online effectively. Currently, abuse training workshops, as conducted by our research partners, are in-person events. We have attended these events. They are usually run by individuals with I/DD (self-advocates) and are highly interactive experiences. It would be an interesting research question to evaluate if the larger abuse training for individuals with I/DD itself could be done online as a way to increase participation. Some research in recent years has explored online education [12, 18] and information retrieval for individuals with I/DD [54]. These could form the starting point for such work.

The main open research questions in this area include:

- How can the learning tool present information about abuse so that it is engaging without being uncomfortable?
- Given that the content can be triggering, what kind of opportunities should be provided for the users to ground themselves?

- How can an online abuse training be designed to deliver the same important content while staying as engaging and lively as the in-person event?

6.4 Opportunity: Exploring the Deployment Workflow for the Reporting Tool

The reporting tool, whatever form it ultimately takes, has to be configurable. Depending upon the location of deployment, the reporting tool should automatically facilitate contact with the appropriate agency at the appropriate time. Overall, the reporting process should be seamless for the individual with I/DD. However, in order for this to happen the agency on the receiving end of the reports may have to adapt their workflow. For one, these agencies may need to be able to receive and process digital abuse reports. Additionally, more resources and training may be needed to manage the non-traditional (i.e., digital) abuse reports that may be produced. Further, we may also have to help individuals with I/DD install the reporting tool on their devices as many of them may not be able to do so, based on our results. Self-advocates and I/DD advocacy groups can play a big role by not only helping individuals with I/DD to install/troubleshoot the reporting tool, but also by training them to use the tool. Of particular interest in this regard are abuse prevention training workshops, often run by self-advocates and self-advocacy groups, where new education modules can be created to help the attendees install the reporting tool and train on it.

The main open research questions in this area include:

- How to change the workflow of the APS agencies to receive and act on digital reports?
- How to adapt the abuse prevention training workshops curriculum to include installation and training on the reporting tool?

7 LIMITATIONS OF THE METHODOLOGY

Even though we obtained impactful results in our two studies, our methodology had a few limitations. The participants in the focus groups were largely recruited at a local disability non-profit's employment program, autism resource center, and day habilitation programs. Consequently, the focus group participants were already part of a community that was helping them with social, job, life, and community skills. It is not completely clear whether the observations reported here will generalize to people with I/DD who do not receive such services. The focus group participants we met had access to technology and had formed opinions on its efficacy with respect to their personal needs. To the extent that we were trying to understand how technology could empower people with I/DD to report abuse, this was fine. However, our approach may not be ideal for many adults with I/DD who do not have the level of resources due to socio-economic conditions or lack of services available to them in their region. For such people, alternative ways of self-reporting abuse have to be considered. Finally, all practitioners who responded to our survey were female, though we did not set out to solicit opinions exclusively from female practitioners. We do not believe that this affected the observations in the paper; however, a more diverse practitioner population could have provided additional perspectives that we might have missed here.

8 CONCLUSIONS

Abuse of people with I/DD is a significant and under-reported problem. In this paper, we set out to understand the current state of abuse reporting by surveying practitioners who help individuals with I/DD post abuse. We also researched the current abuse reporting infrastructure in the US and some of the limitations it has. Based on these findings, we suggested lines of work to empower individuals with I/DD to self-report abuse using a reporting tool based on mobile computing devices. We next conducted focus groups involving individuals with I/DD to understand the viability of such a reporting tool given our community of interest. We then provided a preliminary discussion of four promising areas of research that we believe should be explored on the way to building a self-reporting tool: (1) communicating details of the abuse and injury, (2) protecting the tool from the abuser's actions, (3) facilitating abuse recognition for individuals with I/DD, and (4) exploring the deployment workflow of the reporting tool. We hope these will be useful for researchers and designers working to help individuals with I/DD and other disability communities with recognizing, reporting, and responding to abuse.

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