

Exploring the Requirements of Abuse Reporting for Persons with Intellectual and Developmental Disabilities

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ABSTRACT

Incidents of abuse committed against persons with intellectual and developmental disabilities (I/DD) are woefully under-reported. One way of helping change this situation is to empower persons with I/DD with tools to self-report abuse. During abuse reporting the reporter is requested to provide a variety of information about the abuse and its context. In this paper we wanted to understand which pieces of information are typically needed to successfully report abuse and whether persons with I/DD can provide them. Consequently, we conducted an exploratory survey of the staff at an adult protective services agency in our region and asked them about their *experiences* with receiving abuse self-reports by persons with I/DD. Overall, we found that persons with I/DD are typically able to provide enough information to successfully self-report abuse.

CCS CONCEPTS

• **Human-centered computing** → **Usability testing**; **Accessibility design and evaluation methods**; **Accessibility technologies**.

KEYWORDS

Abuse, Abuse reporting, Intellectual disability, Developmental disability, Safety

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1 INTRODUCTION

In the US, persons 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 [4]. Despite these trends, incidents of abuse committed against persons with I/DD are woefully under-reported [5].

Abuse reporting can be defined as making a formal complaint about an abusive incident and its context to the responsible authorities – typically adult protective services (APS)² – who then initiate protective services for the survivor. When someone reports abuse the APS agency typically requests several classes of information regarding the incident of abuse and its context. *Table 1 shows classes of information requested by our partner APS agency, the Massachusetts Disabled Persons Protection Commission (DPPC), when someone calls their 24/7 abuse reporting hotline.*

In our prior work [5], we argued for the need to develop digital reporting tool that empower persons with I/DD to self-report abuse to APS. The first step in designing such a reporting tool requires understanding two things: (1) which classes of information are typically necessary to make an *actionable abuse report* (i.e., report successfully)? and (2) can persons with I/DD provide the requisite information for an actionable abuse report?

To answer these questions, we conducted an *online survey* of the staff at our partner APS agency (i.e., DPPC) who have experience with *intake* at a 24/7 abuse reporting hotline. The staff working the intake at the hotline are responsible for receiving, documenting, and evaluating abuse reports. We chose to interview staff in this preliminary work to obtain an *experiential* understanding of the difficulties experienced by persons with I/DD (from the perspective of an APS agency) when they self-report abuse.

Our survey was responded to by 19 staff members at our partner APS agency who have intake experience. Overall, we found that persons with I/DD are typically able to provide enough information to make actionable abuse reports, at least in the context of the state of Massachusetts where the research was conducted. Finally, we discuss some of the implications of our findings.

¹Based 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 affects 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].

²APS 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 or adults with disabilities.

Class #	Class of information	Elements
Class 1	Reporter info	Name, Contact information, Relationship to the victim, Language
Class 2	Alleged victim ^α info	Name, Contact information, Demographics, Disability, Language, Assistance needed, Current location, Guardian info
Class 3	Alleged abuser info	Name, Contact information, Relationship to the victim (if any), Language
Class 4	The allegation	Incident date and location, Incident description, Injury
Class 5	Risk to the victim	Risk to the victim, Actions for risk management, Need for medical help, Alleged abuser's access to victim, 9-11 call made?

^α The term victim is what our partner APS agency uses. We will use the term *survivor* unless referring to specific information from the table.

Table 1: Various classes of information typically requested during an abuse report by our partner APS agency in the state of Massachusetts in the US

Related Work: A few 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 [1] [3]. Our prior work [5] was the first to explore the problem of abuse for persons with I/DD and argue for tools to enable abuse self-reporting by survivors with I/DD. To the best of our knowledge, no other work has reported on the process of self-reporting of abuse by persons with I/DD.

2 EXPERIENTIAL SURVEY STUDY

This section describes our study methods (an online survey) followed by our findings. All survey results are described in terms of classes of information listed in Table 1.

2.1 Survey Methods

We deployed an online survey for our study. Our participants were staff at our partner APS agency who had current or past experience with the intake process at the hotline. The survey protocol was approved by the institutional review board (ethics board) of our institutions. Through the online survey we gathered information about the participant's role, frequency of calls received, the participant's opinion about the relative importance of the various classes of information requested during an abuse report, and their experience of situations when the reporter was someone with I/DD. The survey was circulated by our partner APS agency to its employees. Overall, 19 people completed the survey. *Seventeen (17) of the nineteen (19) participants had prior or current experience receiving abuse reports on the hotline.* We had three independent research assistants code each question for common themes and frequency of responses that met those themes. After merging these codings into one datafile, we then analyzed the data based on the frequency of themes that emerged. In the findings below, when appropriate we list counts of the number of participants who gave a particular response. The main **limitation** of this work is that the findings are based on the survey of intake staff at one APS agency with jurisdiction over one state in the US. All the participants were employees from the same agency. Therefore, the responses from our participants were probably limited to their experience in their region.

2.2 Survey Findings 1: The most important classes of information to make an actionable report are the allegation and survivor demographics

We first sought to explore the relative importance of the classes of information within an abuse report when it comes to making the report actionable. For brevity, when describing the relative importance of the elements within a class, we focus on a few of the most important elements as described by our participants.

Most classes of information are *not* required for creating an actionable abuse report. Overall, we found that a large majority of our participants agreed that three of the five classes of information asked during an abuse report need not be provided for the report to be actionable. These were: reporter information (i.e., class 1) ($N = 12$), alleged abuser information (i.e., class 3) ($N = 11$), and risk to the victim (i.e., class 5) ($N = 11$)³. Perhaps most interestingly, these three classes of information that are not essential for an actionable abuse report are the same classes of information some persons with I/DD have difficulty with, as seen in Section 2.3.

Allegation and survivor demographic information are crucial for abuse reporting. The remaining two classes — information about the alleged victim (i.e., class 2) and the alleged abuse (i.e., class 4) — are essential information for making an actionable abuse report. Within each of these classes of information our participants cited several elements as important. For information about the alleged victim (class 2), the elements that were considered essential included: (i) age of the victim ($N = 16$), (ii) primary disability ($N = 8$), (iii) name, contact, and assistance provided ($N = 7$). This makes sense because our partner APS agency has strict jurisdictional requirements as it is primarily responsible for adults with disabilities (in its state) who are survivors of abuse⁴. With respect to the description of the abuse (i.e., class 4), two elements were seen to be important: (i) description of injuries ($N = 13$) and (ii) description of the incident ($N = 12$). Knowledge of any injuries is important to determine the need for emergent medical treatment. The description of the abuse incident was equally important because without the description of the incident it is difficult to determine whether the alleged conduct meets the statutory definition of abuse.

³These three classes of information are primarily asked to clarify jurisdiction, assess risk, and provide as much initial information to the investigator as possible.

⁴The total number of responses exceed the total number of participants (i.e., 19) because individual participants were allowed to choose more than one option.

2.3 Survey Findings 2: Persons with I/DD can provide the information required to make a report actionable

Next we sought to determine which classes of information can be provided by persons with I/DD and do they match with what is required to make an actionable report. We organize our discussion about classes of information below in decreasing order of difficulty for persons with I/DD to provide. Note that the findings discussed here pertain to people who call the hotline and *self-identify* as persons with I/DD. Overall, persons with I/DD can provide sufficient information to enable actionable reports, even if the larger report itself is partially filled out.

Persons with I/DD often could not provide information in classes 3 and 5. *Class 3:* Around half of the participants stated that persons with I/DD have particular difficulty in providing information about the alleged abuser ($N = 9$). This particularly includes lack of information about the identity of the abuser. If the alleged abuser is a direct support staff this may extend to the full name of the staff and the agency they work for as stated by P18, “[Persons with I/DD] did not know [staff] name or which agency they work for.” *Class 5:* A significant number of the participants stated that providing information about risk to the victim (i.e., class 5), i.e., themselves, was not easy for persons with I/DD ($N = 8$). They had particular difficulty in assessing the level of risk they were under, as stated by P6, “[Persons with I/DD] do not know if the abuser still has access to them”. Other times, persons with I/DD found the question itself difficult to understand as stated by P4, “Sometimes the question is confusing”.

Persons with I/DD are largely able to provide information in classes 1, 2, and 4 with some exceptions. *Classes 1 & 2:* For someone self-reporting abuse, class 1 and class 2 are the same information. In this regard, some of our participants ($N = 4$) stated that specific elements of personal information can be difficult for persons with I/DD to provide as stated by P7, “[Type of] disabilities, social security [number], [date of birth]”. The same is true when persons with I/DD report abuse on behalf of others. *Class 4:* Several participants ($N = 6$) stated that when it came to describing the allegation, the biggest impediment was *not* in describing what happened (though there were sometimes clarity issues with the description) but rather where the abuse happened and when. P8 gives a very good example when they stated, “[Persons with I/DD] may not know the proper name of the setting. They call it.. Philip’s house instead of a ... [particular] agency.” Since persons with I/DD can generally provide information in class 2 (alleged victim) and class 4 (alleged abuse), they can make actionable abuse reports.

2.4 Discussion

It should be stressed that this study was conducted in the state of Massachusetts in the US. In our experience, abuse reporting in the US requires similar classes of information to what our partner APS agency requires (as listed in Table 1). However, as noted in our prior work [5], the nature of abuse reporting in the US for people with disabilities changes state to state. Therefore, it is possible that different states in the US may have different or even unique sets of informational requirements, which persons with I/DD may or may not have difficulty in providing. Therefore, our findings should be

seen as evidence of the fact that persons with I/DD can provide enough information to report abuse in the region where the study was conducted.

Moreover, this study was conducted in the context of developing a technological tool to facilitate abuse reporting for people with I/DD. When it comes to facilitating abuse reporting in the US through the use of technology, we believe that the technology should be designed for the region of its deployment. A study similar to this one has to be conducted in any region where such a technology is being considered and the informational needs of the local APS agencies and corresponding capabilities of people with I/DD to provide them should be carefully considered.

Based on the findings of our study, in the context of our region, we suggest two key *takeaways* for designing the abuse self-reporting tool for persons with I/DD. (1) The tool should prioritize the provision of class 1 (reporter information) and class 2 (victim information), and 4 (the allegation) as they are the most important for generating an actionable abuse reporting. As stated before for self-report class 1 and 2 are the same information. (2) The tool should automate the collection of information within classes 1,2, and 4 that may be difficult for persons with I/DD to provide.

Even though the takeaways are written from the standpoint of a digital reporting tool, one could imagine a technological tool that helps with the two takeaways to facilitate easy phone-call-based abuse reporting for persons with I/DD. Over the long term, it would be interesting to see how many of the findings from this paper hold when a digital reporting tool is used.

3 CONCLUSIONS

In this paper, we aim to understand what it takes to actionably (i.e., successfully) report abuse of persons with I/DD. In this regard, we conducted an online survey of the staff in an APS agency. We found that when persons with I/DD report abuse, the information that they provide is sufficient for the APS to facilitate appropriate protective services to them. This is true at least for the region where the study was conducted. As a next step, we plan to look at the historical reporting data from our partner APS in order to develop a broader understanding of the abuse reporting patterns over a longer period of time. Further, such historical data can also be used to understand abuse reporting from the point of view of persons with I/DD through an analysis of the content of abuse reports initiated by them (unlike many other lines of research in accessibility/HCI, directly questioning a person with I/DD about their prior abuse reporting might be severely traumatizing to them and therefore unethical).

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