Victimization Among Persons with Disabilities: Professional Stakeholder Perspectives in Idaho

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We thank the eighteen individuals who participated in our professional stakeholder interviews, as well as the Community Now! group for their time, input, and feedback. We have completed this research for the Idaho Council on Developmental Disabilities and appreciate Executive Director Christine Pisani and the Council's time and assistance in preparing this study. We also thank Amy Cunningham, Executive Director of DisAbility Rights Idaho, and Steven Snow, Executive Director of the Idaho Council for the Deaf and Hard of Hearing, for their time and input.

We want to acknowledge all those working to prevent abuse, neglect, and exploitation among vulnerable adults.

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Victimization Among Persons with Disabilities

Approximately 60 million adults (26%) in the U.S. live with a disability, and in Idaho, 27% of adults (more than 369,000) are living with a disability[1]. There are many types of disability a person may experience, with mobility and cognitive disabilities being among the most common in Idaho[i]. While there are federal and state services and policies designed to support and protect people with disabilities, disability populations are at higher risk for victimization compared to persons without disabilities. For example, in 2019, the rate of violent victimization among individuals with disabilities was 46.2 per 1,000 (age 12 or older) compared to 12.3 per 1,000 (age 12 or older) for those without disabilities – a rate nearly four times higher[2]. People with cognitive disabilities tend to experience the highest rates compared to other disability populations (83.3 per 1,000). Across research studies, the prevalence of lifetime interpersonal violence ranges between 26%-90% among women with disabilities, and between 28.7%-86.7% for men with disabilities[3].

Researchers have emphasized that disability does not cause victimization, but rather persons with disabilities may be more vulnerable to victimization due to a range of factors. These include, but are not limited to, reliance or dependency on caregivers, communication barriers, recognizing actions as victimization (not having the cognitive ability or education to identify inappropriate behaviors), potential offenders perceiving them as vulnerable, discrimination based on ability, and isolation[4]. Additionally, individuals with disabilities are at risk for certain forms of victimization compared to those without disabilities, including destruction of medical/assistive equipment and control over medications[5]. The factors that increase victimization risk are also barriers to identifying and reporting victimization.

Unfortunately, victimization experienced by people with disabilities is often unreported. Although determining the degree of underreporting is hard, data does show that only 38% of violent victimization against persons with disabilities is reported to police

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[i] The Centers for Disease Control and Prevention defines the functional types of disability as follows: mobility is defined as serious difficulty walking or climbing stairs; cognitive is defined as serious difficulty concentrating, remembering, or making decisions; hearing includes deafness or serious difficulty hearing; independent living is defined as serious difficulty doing errands alone; vision refers to blindness or serious difficulty seeing, even when wearing glasses; and self-care is defined as difficulty dressing or bathing. The findings referenced in the first two sentences come from the CDC.

compared with 45% of violent victimization against persons without disabilities. The difference in reporting is greatest for sexual victimization (19% of sexual assaults and rapes against persons with disabilities are reported compared to 36% reported among persons without disabilities)[6]. Abuse and neglect may not get reported due to barriers including: (1) fear of retaliation from the perpetrator, (2) fear of interruption of social and disability-related services, and (3) perceptions that nothing will be done even if the victimization is reported[7]. Victims with disabilities may face additional, external barriers including difficulty communicating[8], challenges in navigating criminal justice systems[9], and negative perceptions of the legitimacy of criminal justice professionals[10]. Individuals with disabilities have explained other reasons for not reporting their victimization, such as dependency on the person harming them for basic needs as well as a general lack of autonomy[11]. Research provides support for these barriers as persons with disabilities are at a greater risk of being victimized by people who are known to them rather than strangers. Paid and unpaid caregivers (which can include family members) are the most common perpetrators[12].

When victimization is reported or observed, response can vary across situations and can be different from response in cases that do not involve vulnerable adults because of the role of social services programs, such as Adult Protective Services (APS). This is one area where there is still little research: understanding what happens when a report is made based on what entity receives that report (APS, police, other social services), what their procedures and decision-making processes are, and whether this influences case outcomes. Numerous state social services and victim service providers may become involved in responding to a person with disabilities after victimization. These providers have different roles and responsibilities, but they are all positioned to connect clients/victims with support services to address the impact of victimization.

Experiencing victimization is associated with numerous negative outcomes, such as depression, PTSD, and long-term physical health consequences, which are more severe for persons with disabilities (particularly those with cognitive disabilities)[13]. Victims often need services to mitigate these impacts however there are challenges to accessing these services, including accessibility, awareness, and service provider communication. Needed services may not be physically accessible (e.g., wheelchair ramp) or accessible in terms of staff capacity to work with persons with disabilities (attitudinal accessibility)[14]. Victims may not be aware of available services or not know where or how to access them. Related to awareness, disability service providers and crime victim service

providers may lack the partnerships or networks needed to be aware of, and refer victims to, those services.

Previous research has identified challenges for social service providers, community resources, and caregivers related to effective response to victimization. These include identifying victimization (particularly abuse and neglect)[15], access to needed resources, and collaboration among service providers[16]. Counseling and trauma-informed care are important resources for persons who have experienced abuse, though they are not always accessible to individuals with disabilities. Barriers to delivering these services include a lack of service providers, staff turnover, and lack of training[17].

Idaho has network of federally mandated resources inclusive of the Idaho Developmental Disabilities Council (advocacy, public policy, and service system improvement), DisAbility Rights Idaho (protection and advocacy), and the Center on Disabilities and Human Development (training, services, technical assistance, research)[18]. In addition, there are state statutes relating to the protection of vulnerable adults, various services for individuals with disabilities, and specific rights of persons with disabilities[19]. Though services are in place, community stakeholders have expressed concerns about identifying, reporting, and responding to victimization experienced by people with disabilities in the state.

This report is a first step in systematically learning about these issues in Idaho and focuses on the experiences and perspectives of professional stakeholders working in disability and victim services. The current study details findings from in-depth interviews on the strengths and challenges in delivering disability and crime victim services to individuals with disabilities who have been victimized in Idaho.

Research Description & Findings

Our research team was contracted by the Idaho Council on Developmental Disabilities to provide several studies relating to the victimization of persons with disabilities, aimed at reflecting cross-disability experiences. This is the first of those studies and focused on gathering interview data from key stakeholders who may work directly or indirectly with the populations of interest[ii]. Given the emphasis on better understanding processes, procedures, and responses, as well as perceptions of victim experiences, stakeholder interviews were determined to be an appropriate and necessary means of gathering data about these topics from those involved in responding to abuse, neglect, and exploitation or supporting victims in accessing services. Individuals were interviewed as representatives of their agency/organization/office/unit/division, and what we refer to as 'entity' (see Figure 1).

Figure 1. Common Terms

Stakeholder

The term 'stakeholder' in this report refers specifically to professional stakeholders: those who work with disability communities, in disability service provision, or in entities that may respond to or serve persons with disabilities after experiencing victimization.

ANE

ANE stands for 'abuse, neglect, and exploitation'. This is the most common phrasing for discussing victimization among vulnerable adults. In this report, ANE and the term 'victimization' are used interchangeably, though criminal victimization experienced by persons with disabilities may extend beyond ANE.

Entity

The term 'entity' is used to describe the stakeholders' places of work. To maintain confidentiality and reduce the use of multiple or changing terms, 'entity' is used when referencing the interviewed stakeholders' place of work.

[ii] There are other stakeholder groups, most notably those living with disabilities not captured by the above definition. This study is focused on the perspectives of those working in the field. Upcoming planned research in the state will be engaging additional key stakeholder groups.

A list of relevant stakeholders, defined as entities that may be involved in identifying, responding to, or serving vulnerable adults who experience victimization, was developed. This list included a range of entities and the contact information for at least one individual working at the entity. Input on the list was collected at meetings of the Community Now! group and the Idaho Council on Developmental Disabilities. We also conducted internet searches for relevant professional stakeholders to develop a comprehensive list. The study design and methodology were approved by Boise State University's Institutional Review Board (IRB)[iii]. All interviewees provided informed consent, and participation was confidential.

Sample

Initial invitations to participate (n=48) were emailed in January 2022. Initial responses included 10 referrals for other relevant stakeholders, some in place of our initial contact and some in addition to the initial contact. In total, 58 interview invitations were sent. The potential sample (including referrals) represented 46 entities across the state. The stakeholder list included state entities responsible for providing services to persons with disabilities and crime victims; entities that provide services in the community to crime victims and/or persons with disabilities; and entities that work with immigrants, refugees, and non-English speaking clients who may be crime victims and/or have disabilities. Follow-up emails were sent to those who did not initially respond, as well as follow-up emails to those who indicated interest initially but had not committed to scheduling. In total, we received 30 responses to our requests: 22 expressed interest in participating and 18 were successfully scheduled for interviews. One interview consisted of two people from the same entity, resulting in a sample of 17 interviews representing 15 different entities[iv].
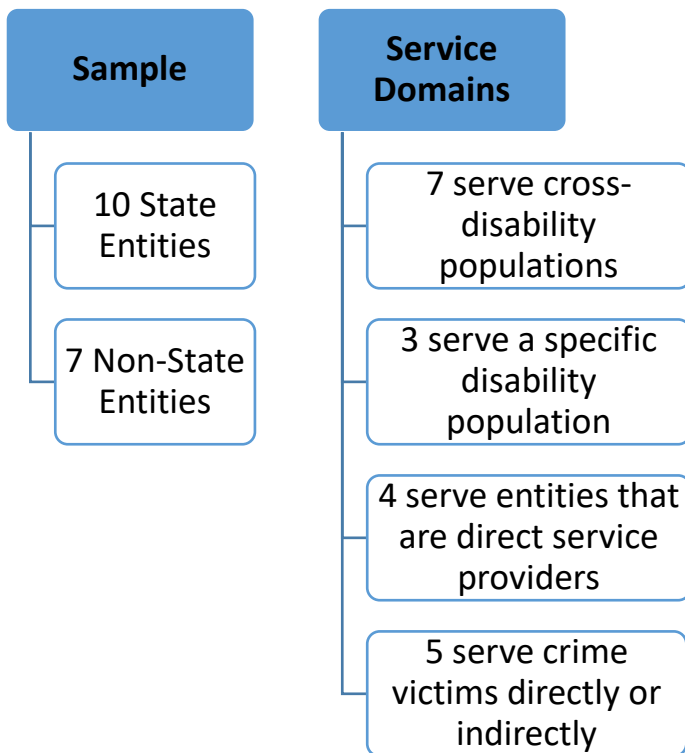

[iii] IRB Protocol Number 000-SB21-181
[iv] Two separate interviews were with people representing different roles in the same entity, and thus were providing different viewpoints of that entity.

Figure 2. Study Sample

Sample
- 10 State Entities
- 7 Non-State Entities

Service Domains
- 7 serve cross-disability populations
- 3 serve a specific disability population
- 4 serve entities that are direct service providers
- 5 serve crime victims directly or indirectly

Interviewees' identities are confidential and thus the sample is described in broad terms. Represented among the interviews were state entities (n=10) and non-state entities (n=7). Entities can also be described by when they are involved with clients: more on the "front end" by identifying potential abuse, neglect, and exploitation, responding to initial reports of such action, or engaging in prevention efforts (n=5); more on the "back end" becoming involved after another entity engaged in an initial response, being responsible for investigation, or serving clients after some form of investigation or response (n=5); or both front and back-end involvement (n=7). Among represented entities, seven serve a range of disability populations (cross-disability), three serve a specific disability population, four serve programs or agencies that in turn serve people with disabilities or crime victims, five serve crime victims directly or indirectly, and three serve persons with mental health needs in addition to disability. In total, 10 of the represented entities exclusively serve disability and aging populations. The remaining seven serve a range of populations including, but not limited to, persons with disabilities.

Interview Format

Five research questions were the focus of this study (see Figure 3). To answer these research questions, a list of interview questions was created. Interview questions were developed based on: (1) relevant questions from the Idaho Council on Developmental Disabilities, informed as well by Community Now!,[v] (2) review of other studies that have used interviews or focus groups to gather information about disability and victimization,[20,21,22] and (3) prior research using stakeholder interviews in the state[23].

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[v] https://healthandwelfare.idaho.gov/services-programs/community-now

Questions centered on several key topical areas including risk of abuse, neglect, and exploitation among persons with disabilities; how the work of the entity may overlap with victimization experiences among persons with disabilities; how the entity responds if made aware of potential victimization or how the entity serves persons who have experienced victimization; policies and/or procedures that are in place relevant to response or service provision; relevant training and training needs; resource needs; and perceptions of client or service population experiences relevant to the study focus.

Figure 3. Research Questions

Research Questions

- What are stakeholders' perceptions of victimization risk among persons with disabilities?
- What are stakeholder entities' policies and/or procedures related to victimization reports and response to reports? What works well and what can be improved?
- What are stakeholder perceptions of clients' (victims') experiences with reporting and response? What are perceptions of service seeking experiences?
- What training and resources do stakeholder entities have and what training and resources do they need?
- What outreach and community education do stakeholder entities engage in? What outreach/community education/awareness is needed?

Due in part to the COVID-19 pandemic and in part for participant convenience, all interviews took place remotely through the Boise State University Zoom platform with data stored on a secure server. Each of the interviews lasted approximately 30 to 60 minutes and was conducted by one of the two lead researchers, with 16 of the 17 interviews conducted in a one-on-one format, and one interview conducted with two interviewees from the same entity.

The stakeholder interview transcripts and interviewer notes were read and annotated to identify themes and key perceptions (a process called "coding"). Codes were based on the topical areas of the interview questions relevant to answering the research questions. For each code, the relevant content was re-read to identify sub-themes related to content areas. Summaries of these themes and direct quotes that support these themes are presented below. Unless otherwise noted, findings are relevant cross-disability as most stakeholder entities serve multiple disability populations.

Results

Victimization Risk

When asked directly if persons with disabilities are at a higher risk for victimization, stakeholders said they are (see Figure 4). One stakeholder referenced a statistic that persons with disabilities are at four times the risk, while other stakeholders indicated they believe specific populations are at risk, based on their professional experiences[vi].

Figure 4. Stakeholder Perceptions of Victimization Risk

Are persons with disabilities more vulnerable to victimization?	Why are they at higher risk?	At risk for what?	Who are they at risk from?
• "Absolutely" (S1) • "100% yes" (S11) • "individuals with developmental disabilities are definitely more at risk than some other populations, but I would also say that individuals with Alzheimer's or related dementias are equally as vulnerable" (S3)	• "they're not able to speak up for themselves" (S5) • "they're vulnerable in a multitude of ways and they're dependent on staff to meet their daily needs" (S1) • they are targeted by criminals because of their actual or perceived vulnerability	• Abuse • Financial exploitation • Neglect • Fraud or theft • Sexual violence • Trafficking • Domestic abuse	• Caregivers • Staff (e.g., in living facilities or providing in-home services) • Family members • Roommates • Spouses • Friends • Acquaintances or people who just have access to individuals

Three stakeholders specifically indicated that offenders may target people with disabilities for victimization because they are seen as weak or vulnerable or easily groomed for specific forms of victimization. Stakeholders also described how dependency or reliance on others (for services, support, day-to-day functions) can place

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[vi] Including people with intellectual or developmental disabilities as well as individuals with Alzheimer's or related dementias, the elderly, persons with disabilities who have less stability in their lives.

people at higher risk. One stakeholder explained that violent victimization can lead to disability – cognitive or physical – and that in turn can make that person more vulnerable to future victimization. As another pointed out, the terminology 'vulnerable adult' would not exist if there were not people who are at heightened risk.

Policies, Procedures, and Response to Victimization

Stakeholders described how they would become aware of ANE and/or how their work may overlap with victimization among persons with disabilities. Based on the interviews, we identified two common methods through which stakeholders learn of potential ANE: 'entity-to-entity' and 'individual-to-entity' (see Figure 5).

Figure 5. How Stakeholders Learn about Victimization

Entity-to-Entity Reporting	Individual-to-Entity Reporting
Several stakeholders indicated they most commonly learn of ANE when other entities contact them to let them know of a potential issue/concern or contact them in their capacity as mandatory reporters. Some of these entities are contacted in their capacity as investigative bodies, but non-investigative entities may also be contacted by other entities. Entities may be responsible for investigating an allegation of ANE directly or some aspect of a responsible facility or service provider.	Several stakeholders indicated they most commonly learn of ANE through direct interaction with: (1) victims seeking help or resources or (2) from concerned family, friends, neighbors seeking resources on behalf of the person experiencing harm. Sometimes direct contact is made explicitly because of ANE. Other times contact is made in the process of seeking general resources or assistance, and through conversation the entity may become concerned that someone is experiencing ANE. Individual-to-entity contact was described by those that provide victim services and by those that provide services to persons with disabilities.

Stakeholders were asked whether their entity has any specific policies, protocols, or procedures in responding to suspected ANE or reports of ANE. The majority indicated that there is some form of policy or protocol for response, but these policies/protocols vary entity-to-entity. Variation exists in whether policies are: (1) documented in writing, (2) have been developed through experience-turned-unofficial protocol, or (3) are discussed in training or onboarding though not part of an actual policy document. Any entity with mandatory reporters is responsible for following relevant state laws. State codes or statutes influence or define policy for state stakeholder entities.

Multiple stakeholders indicated that procedures include reporting to relevant parties (e.g., adult protection services, Medicaid quality assurance, police). Stakeholder entities with investigatory responsibilities have guidance relating to investigative procedures, however stakeholders also indicated that procedures may not look the same throughout the state among entities with multiple or regional locations.

Stakeholders identified aspects of response that work well and aspects of response that need to be addressed or improved. Some of the themes appear on both lists. For example, staff are seen as a strength for response in some situations or by some stakeholders and a challenge in other situations or as perceived by other stakeholders.

What Works Well

Multiple stakeholders acknowledged the work of **dedicated staff** as strengths for the entity and in responding to reports of ANE (see Figure 6). These stakeholders recognized the quality and experience of team members, including the ability to build rapport and effectively engage with their service populations. For example, Stakeholder 1 explained "*having an experienced staff that are trauma informed [...] makes a huge difference*". The key role of 'service coordinators' as a point of contact and facilitators for clients in response to ANE was also identified.

Staff strengths may also be related to what some stakeholders described as beneficial inter-entity **collaboration** on investigations, as well as coordination with other relevant entities on behalf of clients. A final staff-related strength was not specifically linked with entity collaboration, but rather a style of service provision where an **individualized approach** is taken with each client to assess and meet all potential needs.

Figure 6. What Works Well in Responding to Reports

Reflecting on their own place of work, a few stakeholders perceived various **aspects of their reporting policies or protocols** as strengths, including: (1) the effort made in following-up on complaints or suspicious circumstances, (2) the ability to receive and follow-up on anonymous complaints, and (3) state and entity rules regarding reporting were perceived as increasing reporting or awareness of potential incidents requiring response. Another internal strength has been **recognizing potential weaknesses** and addressing those, such as enhancing electronic case tracking. A benefit of this practice is the ability to better determine whether policies and procedures are being adhered to consistently across and within cases.

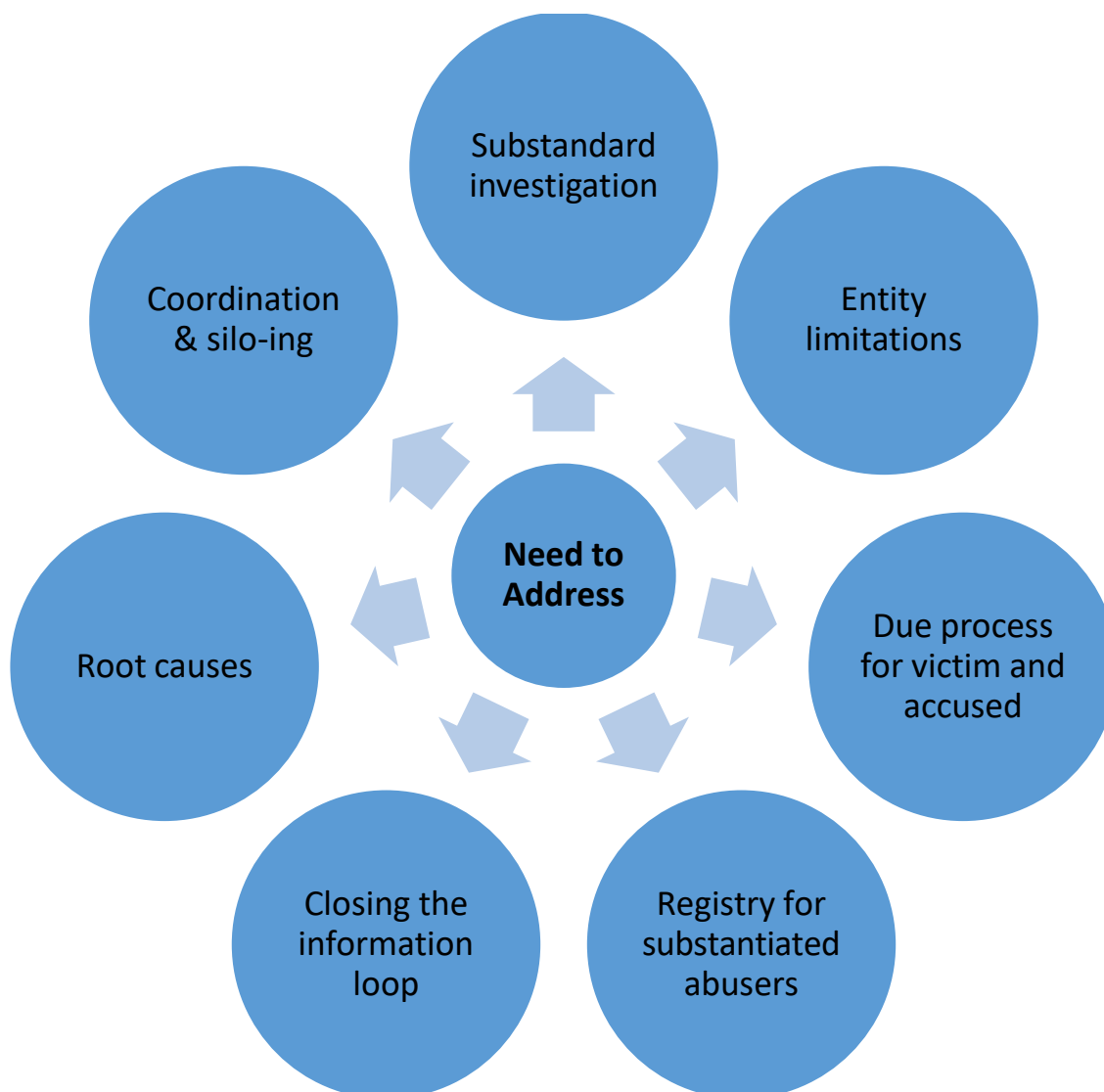Though much emphasis is placed on what works well in responding after-the-fact, some stakeholders emphasized services they offer that could **reduce or prevent ANE**. Caregiver stress is one component of this: "*those caregivers, some of them are in great stress, you know they're burned out there, doing something that they were never taught to do in the first place. You know, we are taught to take care of babies when we're little, but nobody takes us aside when we hit our teens and says, 'this is how you're going to take care of an adult'*" (Stakeholder 15). In recognizing the role of caregiver stress, some entities provide services or connect caregivers with resources intended to alleviate or reduce that stress.

What Needs to Be Addressed

Stakeholders are concerned about internal decision-making among facilities that have an obligation to investigate claims of ANE (see Figure 7). Specifically, stakeholders are concerned with situations where some are **failing to investigate** or the "*investigations they conduct are […] substandard to what is expected of them*" (Stakeholder 3). Further, for entities that conduct internal investigations, those investigations are not always known to relevant oversight entities (when they should be).

Several stakeholders also highlighted the **limitations of entities** involved in investigations and/or substantiating ANE or violations. Their descriptions indicated a two-pronged challenge to effective response: first, people in the community, and sometimes other relevant professional entities, are not aware of their limitations or specific authority and thus believe they can do more than they can; second, their authority is limited which can lead to unsatisfactory results in cases of ANE and/or the case may be passed on to criminal justice authorities, but those results may also be unsatisfying. A couple stakeholders specifically made comparisons between child cases and adult cases, underlining the more extended authority for action in child protection cases compared to vulnerable adult cases. As Stakeholder 1 explains: "*it's not like child protection where law enforcement comes in and says "oh my gosh, you're in imminent danger we're taking you into custody," that doesn't happen in the adult system*" (Stakeholder 1).

Figure 7. What Needs to be Improved

- Substandard investigation
- Coordination & silo-ing
- Entity limitations
- Need to Address
- Root causes
- Due process for victim and accused
- Closing the information loop
- Registry for substantiated abusers

One theme that many stakeholders touched on is what we describe as tension between protecting persons with disabilities and holding those perpetrating ANE accountable. This tension also showed up as a debate regarding **due process** for victims and due process for the accused. Some stakeholders described this as their own tension or tension they see between stakeholder entities, and this was also notable in comparing different stakeholders' comments relating to response. Stakeholders, knowing that persons with disability are at heightened risk for ANE, want to have mechanisms in place for preventing, identifying, and responding effectively to ANE. Some stakeholders suggest that situational factors and degree of harm should be considered in

distinguishing between the punishment of caretakers who are malicious and caretakers who lack training or resources. If malicious, stakeholders suggest accountability may look like being fired and placed on a substantiated abuser registry (which does not currently exist). If it is due to lack of training or resources, then some stakeholders suggest accountability should consist of education and resources needed to improve caregiving, possibly inclusive of a mediation or restorative justice approach.

This tension was also touched on by stakeholders that work directly with crime victims and/or persons with disabilities experiencing abuse in situations where a caretaker is a loved one (parent, spouse, adult child) and the person experiencing ANE wants the ANE to stop but does not always want their loved one to be removed or arrested.

Related to the above-described tensions is the recommendation from several stakeholders for a **registry**, to identify direct care staff who have been substantiated for abuse. As Stakeholder 14 explained:

"there is a registry for certified nursing assistants in nursing homes, and so, if there's any abuse and neglect they can be reported to the Department of Health and Welfare its licensing certification, and they'll do an investigation and if they are, if that allegation is substantiated, they are put on the registry - the exclusion registry - and they will fail any background check to work with vulnerable adults […] but that same process does not exist in assisted living facilities or any intermediate care facilities or residential rehabilitation [...so] there's really no way for there to be a civil process to get someone on the registry."

One stakeholder described the lack of a registry (or ability to stop an abuser from working with vulnerable adults) as a system failure. And another described the impact of not having some form of registry:

"bad employees just get passed around and people just keep getting revictimized and revictimized and there's trauma and they're [the perpetrator] just leaving this path of victimization and it's just... and then they're more vulnerable to the next person that's been passed around, and then the next person that's been passed around and it's just, it's such a perpetual problem" (Stakeholder 2).

The next area of need involves communication and '**closing the loop**' on reports and investigations with involved parties. This is another area where some stakeholders recognize that due process must be considered, and with that in mind, see a need to

improve communication about case outcomes. Several stakeholders indicated that if the allegation is serious enough to constitute a crime, they report it to police (in addition to relevant state disability entities). However, stakeholders, particularly those that we categorized as 'early' or 'front end'-involved, also expressed that sometimes they do not know if the state disability entities, police, and/or prosecutors reviewed the matter, nor why or how decisions are made. As Stakeholder 9 explains *"[there is no] statutory obligation to inform us of the conclusion of their review or whether they found a credible allegation when they investigated. We are never aware of what happens, so that's a gap, a systematic gap"*. The majority of stakeholders said that they either sometimes or often do not know the outcome of a case, even though some state systems are set-up to allow for this follow-up. Most of them wish that loop was closed, although a couple were okay with not having that information.

Stakeholders, some directly and some through example, indicated the importance of identifying the **root causes** beyond just responding. This often came up in the context of facilities that employ many caregivers and providers, some of which may engage in ANE. In order to prevent facilities from having repeat offenses, resources should be directed at the causes for staff misconduct and/or criminal offending:

"it can get into a pattern, where the provider says, here's my corrective action I'll make sure it doesn't happen again, but yeah the same thing happens again and so, it's kind of like a loop sometimes that happens and I think the piece that needs to be addressed is the root cause because if the provider can't hire staff that are competent to care for individuals then they're going to have repeat offenses, if they can't afford to train their staff appropriately, they're going to have repeat offenses" (Stakeholder 4).

Coordination with other entities when there is a report of ANE was also described as a need. When asked to describe the experience of working with other entities, stakeholders identified effective working relationships (described in the previous section) and tense working relationships. Importantly, there was not one entity singled out as "a problem" by all stakeholders, rather, different stakeholders have different experiences with a given entity. For example, one stakeholder shared having a less effective relationship with entity A, while another stakeholder referred to entity A as a great partner. One stakeholder explained that relationships with any given entity can vary over time depending on the parties involved and depending on external pressure such as legislative concurrent resolutions around collaboration that (more or less) force

parties to the table. Information sharing is one area that was identified as a challenge to inter-entity coordination, as well as "finger pointing" regarding responsibility, and a perceived lack of willingness to engage cross-entity to create *systematic* change.

Related to coordination, five stakeholders spoke to "**silos**" specifically, expressing concern about the separation of entities that provide services to persons with disabilities. The number of different entities that a person with disabilities experiencing ANE (or someone acting on their behalf) could potentially make initial contact with, paired with confusion around whom they should contact first, how they should make contact, and what to expect when they do so, is a potential consequence of 'silo-ing' as well as a factor resulting in low reporting. On the positive side, stakeholders offered evidence that developing connections and relationships can lead to better outcomes. Some stakeholders provided examples of relationships between entities that were tense historically (due in part to confusion over roles, responsbilities, and/or authority) and through intentional efforts to educate and partner, those relationships or interactions have improved.

Perceptions of Client/Victim Experiences Reporting and Accessing Services

Stakeholders were asked several questions relating to their perceptions of their service population's experiences reporting and/or accessing services.

Reporting and Reporting to Whom?

Although reports are certainly made, stakeholders emphasized that underreporting is a significant issue in estimating the true scope of the problem and responding comprehensively.

There is general agreement among stakeholders that when reporting does happen it is most likely to be to a trusted caregiver, friend, neighbor, or a direct service provider; followed by being identified by a health care provider or those with training in identifying ANE; with clients being least likely to report directly to police. Stakeholders representing entities involved in investigations indicated that entities report to police when complaints rise to a criminal standard or present imminent threat to health or safety, and that sometimes police inform them of a case. Additionally, stakeholders who described their dedicated and skilled staff as an asset in ANE response also indicated that these staff take complaints, especially self-reported victimization experiences, with sympathy and care.

Challenges or Barriers to Reporting

Stakeholders identified a range of barriers to reporting, and explanations for their assessments of underreporting which we have grouped into seven categories (see Figure 8).

Figure 8. Barriers to Reporting
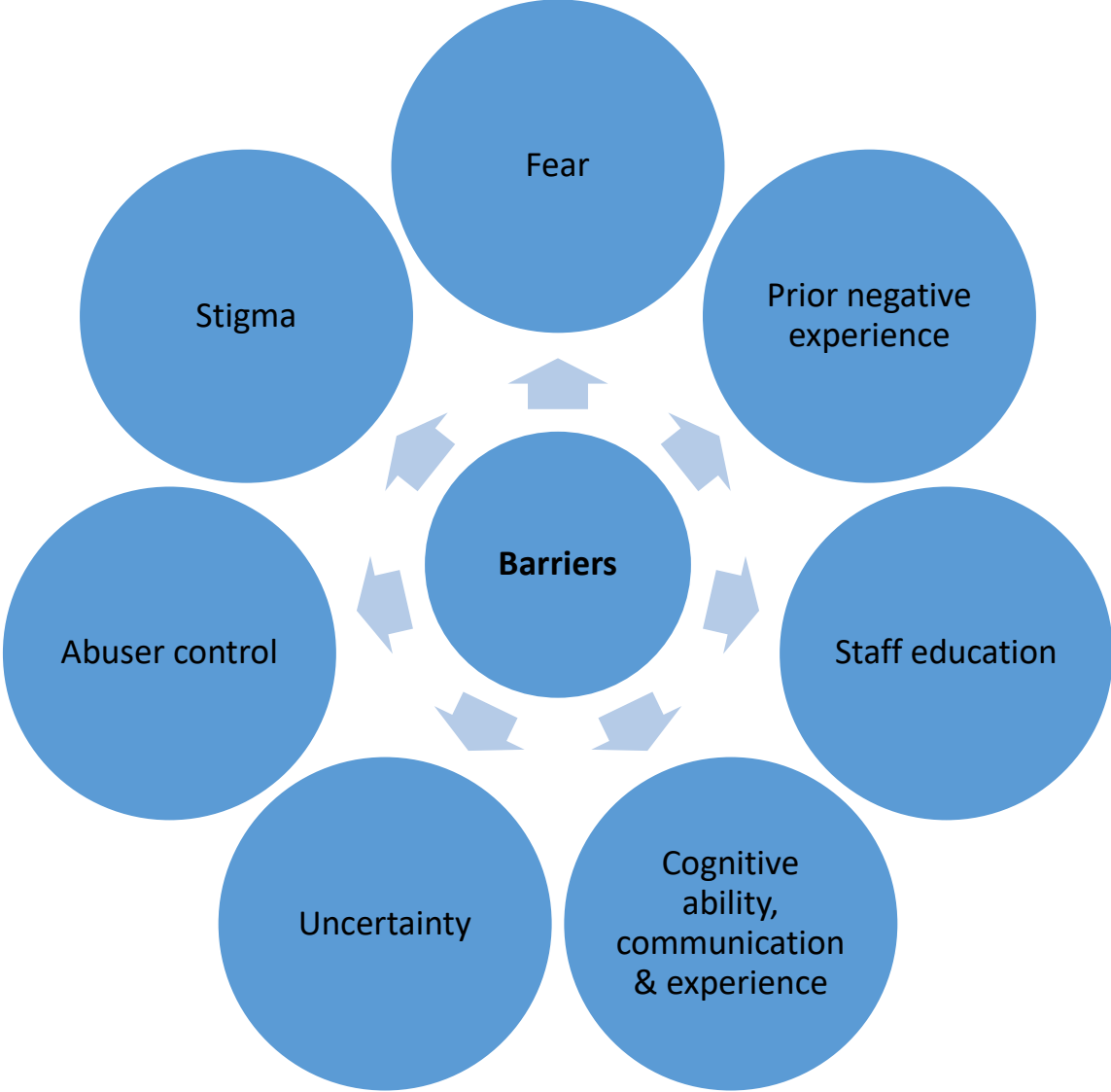
Stakeholders perceive **fear** as the primary barrier to reporting. Fear of getting someone – especially their primary caregiver – in trouble; fear of not knowing what will happen when they do report, including not knowing if they will remain safe through the process or after; fear of retaliation (for both victims and staff); and fear of their housing

situation changing or losing housing. Given its prevalence, below are two stakeholder quotes describing the impact of fear.

"I would say number one is the fear of retaliation, whether it's a resident that's living in a facility who's afraid that they'll be discharged if it's found out that they lodged a complaint. Or if it's a staff member in a facility, they often talk to us about being afraid or wanting to stay anonymous because they're afraid that they'll be fired if the administrator finds out that they called [the entity]" (Stakeholder 3).

"you'll [victim] definitely think twice about reporting anything about your provider, if you know that your living situation is on the line" (Stakeholder 12).

Prior negative experience encompasses several potential challenges, including personal prior experience in reporting and not being believed, knowing someone who reported and was not believed, and awareness of others' reports that did not have a positive or beneficial outcome. Stakeholder 13 describes it like this: "*within the community there is a reputation that it's not even worth reporting or worth seeking help. I've heard a lot like 'yeah we had a friend who did it, nothing happens, so why would I take the chance on reporting this or seeking help?'*"

Stakeholders indicated that for some locations and for some positions, staff do not have the knowledge or skills to identify ANE (especially exploitation) that a client or patient may be experiencing. They also perceive that some staff do not have the needed skills to communicate effectively with a client to learn of ANE. And they describe that staff do not always know about the ability to submit anonymous or confidential reports to some investigative entities. All these barriers could be addressed through **staff education and training**.

Five stakeholders noted barriers associated with the victims' **cognitive abilities, communication abilities, or their experience** or knowledge of the world. For these vulnerable adults, they may not realize that they are experiencing abuse, they may not be able to express themselves or communicate with those around them to share what is happening, or they may have experienced various forms of ANE their entire lives and not recognize those actions for what they are.

Uncertainty also plays a role. Just as staff may not recognize ANE or know where or how to report, persons experiencing ANE may also not know who to reach out to first, and they may get sent to multiple places and sharing their story multiple times, enhancing

the burden of reporting. Repeated sharing of their experience can also have another negative consequence: changes in the story may be seen as evidence of untruthfulness when the ability to remain precisely consistent can be challenging for persons who have experienced trauma (regardless of disability).

If the **abusive person** is the one who communicates with the outside world on behalf of the person being abused, that presents a significant barrier to reporting. For example, if police respond to a situation and the victim needs an interpreter that the police do not have, the abuser may offer to serve as that interpreter, hiding the truth of the situation. Or in situations where the person experiencing abuse may have an intellectual or developmental disability, they may not be perceived as believable or reliable as their abuser who does not have a disability. Additionally, the isolation of some persons with disabilities poses challenges to reporting, especially if the abusive person is a primary caregiver or the victim's only regular contact.

A couple of stakeholders pointed out a societal or systematic barrier: **stigma**. Stakeholders expressed frustration that society tends not to see people with disabilities as having value. And stigma associated with populations that are undervalued may lead to someone not identifying as a person with a disability, and thus not accessing services. For example, Stakeholder 8 shared "*figuring out how to connect people to resources that could really help them without like, trigging that stigma, would be really helpful*". This factor is distinctively important to consider in the context of barriers to reporting and barriers to service seeking.

Perceptions of Service Seeking and Service Needs
We identified four areas or categories of perceived service needs for clients (see Figure 9).

Stakeholders expressed concerns about access to **counseling** services from those who have expertise in disability. While counseling for someone who has experienced ANE or victimization is a standard service, finding the right counselor for some populations of persons with disabilities can be challenging. Another challenge is overcoming stereotypes that lead people to believe certain populations cannot benefit from common forms of trauma therapy.

Stakeholders expressed concerns about there being a systematic way to refer clients to **behavioral and mental health** to help address trauma. While there is a sense that this

Figure 9. Stakeholder Perceptions of Service Needs

Counseling

Accessibility

Service Needs

Behavioral & mental health

Support groups

does happen for some, the concern is that without a mechanism in place, it may not be happening for everyone. A need for services for persons with dual diagnoses (defined as persons with cognitive or developmental disabilities and mental health diagnoses) was emphasized by multiple stakeholders. These stakeholders recommend improved capacity in provider systems to work with dual diagnosis clients, as well as clients who have other forms of disability and also experience mental health needs.

Stakeholders (especially those in victim services) perceived that clients would benefit from **support groups** with people who have similar experiences. Simply having places for people to go to communicate about their experiences, be with others who have similar experiences to themselves (both disability and victimization) and get directed to the right resources is perceived as a need. Currently there is not a means for findings or organizing such support groups. Taking the idea of support in a different direction, some stakeholders recognized the need for caregiver supports, particularly familial caregivers without professional training.

Accessibility of services for all forms of disability is a significant hurdle. Stakeholder 6 listed the many of the barriers related to accessibility:

"So, are they accessible [...] you know there's a whole bunch of people with disability, so if you're deaf, are they going to provide sign language interpreters, captioning? If you're blind, are they going to provide alternate formats, are you going to be able to read

information, you know by a screen reader? If you're physically, have a physical disability, are you going to be able to access, you know, the building or you'd be able to go to a shelter? If you have intellectual disability… I mean there's just… is it understandable information? Are people comfortable working people with disabilities, I mean it's the gamut, those are a lot of barriers."

A few stakeholders described a strong desire to build relationships with disability services to make sure they are making services accessible. They currently perceive victims with disabilities that come to them as having to *"jump through hoops"* (Stakeholder 16) to piece together relevant disability and victim services. Building deeper relationships between disability service providers, the disability community, and victim service providers was suggested as one potential solution for this issue. Beyond accessibility in a disability context, there are accessibility issues that are not specific to disability, including that entering new systems (healthcare systems, government systems) can be confusing and unclear, and that physical location influences accessibility as persons in in rural areas may have to travel hours to access services.

Training and Training Needs

Almost all stakeholders indicated access to some training related to disability and ANE. Only two said that there is not specific training through their work, and another referenced training that they came into the position with (rather than training provided in their current position). Among those that indicated having training, impressions of the training varied. Some expressed trainings being high quality and helpful, others indicated that training was more limited or lacking in certain areas. Among the types of training, training related to investigations, crisis intervention, and clinical trainings were mentioned, in addition to basic training on disability and/or victimization. Six stakeholders spoke to also providing training to state and/or non-state entities and groups on topics relevant to disability and/or ANE.

Training Needs

Stakeholders were asked what, if any, training they would like to have access to that is not currently in place. Given the different entities stakeholders represent, there is a range in desired training. Some training topics are currently covered to some extent, but stakeholders want more training in those areas, while other training some stakeholders currently have access to, and others do not.

Multiple stakeholders want **interview training** for themselves or other staff (see Figure 10). Specifically, they want to be better able to interview persons with disabilities, primarily intellectual and developmental disabilities, effectively and appropriately. Related, stakeholders also indicated that training on how to build rapport with clients/service seekers would be beneficial to making services better.

Figure 10. Training Needs

Stakeholders see **specialized training** as beneficial for staff that work with specific populations, and targeted training to develop key skills for relevant staff (e.g., crisis intervention, interviewing, communication). Stakeholder 14 provided an example of why this is important: *"there's been cases where […] untrained professionals or untrained law enforcement showing up and interact in a way that's not appropriate for*

the population. You know, it leads to, you know, the victim harming themselves or others".

Stakeholders indicated that, for college students planning to work in disability services and for staff new to the field, there should be organized **on-the-job training**. Another stakeholder described a similar desire for hands-on interpersonal skills training, not just online training. Stakeholders also indicated a desire for **supervisory training** for those responsible for other staff and facilities.

Among the stakeholders we interviewed that might be involved in reporting a claim of ANE, requests were made for facility staff to have enhanced training related to **identifying** the signs of ANE and **reporting** ANE, including in situations where they may report to a supervisor instead of an investigative body directly, and perceive supervisor inaction. This would include making sure staff know where they can report anonymously or confidentially.

For stakeholders that indicated not having policies or not having explicit or detailed policies, training related to **policy development** and best practices is of interest.

Stakeholders spoke to several trainings that they would like to have in **collaboration** with other entities. Specifically, training that engages disability entities with each other, disability service providers with victimization service providers, and training that engages police and prosecutors with disability service providers. Some stakeholders suggested training or collaborative opportunities for disability and relevant entities to learn more about what each other does including procedures, authority, and limitations would be beneficial. In terms of training with criminal justice professionals, stakeholders expressed wanting a better understanding of what to do to preserve evidence, a scene, and in interacting with the person impacted, so that the possibility of prosecution is not at risk. In addition to inter-entity trainings, one stakeholder suggested that trainings led by, or inclusive of, persons with disabilities would be an asset so that staff can learn directly from the populations they are working with.

Though not a specific training topic, some stakeholders indicated a need for access to contemporary and ongoing training rather than one-time training during the onboarding process. A couple of stakeholders also noted the limitations to training, acknowledging a need for training to be effective in their position and have the skills they need to fulfil their role, but cautioning against training being seen as the complete solution: *"it's tricky, trainings tend to be the go-to thing, but we know that's not enough because it's*

not changing behaviors or practices" (Stakeholder 13). These stakeholders described training as just one piece of the puzzle in enhancing response.

Resource Needs

Stakeholders were asked about their entities' resource needs to enhance or expand their ability to respond to ANE. Funding – for a variety of purposes – and staffing were the two most prominent needs. However, stakeholders also identified other resource needs directly or indirectly related to funding and staffing (see Figure 11).

Figure 11. Stakeholder Entities' Resource Needs

A top priority for several stakeholders is **staffing**. They explained that serious understaffing has a direct impact on service provision and the ability to respond to ANE. Stakeholders described being desperate for "bodies" and being in the middle of a "direct care workforce crisis". There are significant staff shortages, including skilled positions that are vacant, and (for relevant stakeholders) caseloads that are increasing but no additional staff to meet demand. Stakeholders indicated several negative consequences of understaffing, including having to turn people away or refer them to other entities, and impacts to ANE response. Understaffing means there can be (1) reductions in effective supervision or oversight of care facilities, (2) that staff do not have the time to improve their skills or learn from experiences, and (3) that clients or staff may not report ANE due to the inability to replace care workers that are fired, or accountability may be reduced in general because

of staffing shortages. Stakeholder 17 described the link between staffing concerns and neglect: "*probably 50% of the people in facility living right now are going, are experiencing some kind of neglect and it could even be higher than that and that's not intentional that's because there's no staff, um, but it doesn't, you know, neglect is neglect it doesn't matter if it's intentional or not.*"

In addition to simply needing more staff to fill vacant positions, stakeholders spoke to needing various resources related to **supporting staff**. For staff that communicate with clients about coordinating services, there is a desire for scripts that could be used to cue staff about what to say if they become suspicious that the person may be experiencing ANE. A few stakeholders indicated that a detailed list of *accessible* resources in the state would be beneficial in coordinating with clients. Stakeholders would like to be able to provide guidance to facilities/providers on *how* to improve when issues are identified, instead of simply telling them to fix the problem or figure out how to fix it on their own. Emotional support and mental health resources for staff to reduce secondary trauma effects and burnout was also a perceived need. And, recognizing turnover and burnout, stakeholders want better wages for staff that reflect the value of their work in society.

Just as this need was pointed out in considering clients' experiences in seeking services, access to **specialized positions** (including clinicians and counselors who can work with specific disability populations, cross-disability populations, and dual-diagnoses populations) that can provide effective therapy for persons with disabilities are needed resources. More broadly, a need for community resources dedicated toward **crisis care** that is not limited to hospitalization was identified.

Although several of the previous resources also require funding, stakeholders indicated some specific resources that they need or would typically provide but cannot do so when budgets are tight, or when the additional **financial resources** are not there. These include: (1) multi-entity collaboration, (2) resources for community engagement, (3) financial support for training and education, and (4) extending services across the state and to underserved populations throughout the state. In other words, important, even critical, components in response become luxuries in the context of tight resources.

Several stakeholders shared that they would like to see strong state and **legislative support** (financial and otherwise) for addressing the intersection of disability and victimization.

Outreach and Awareness

Several stakeholder entities are engaged in various forms of community outreach, education, or awareness efforts. Some entities are involved in outreach in collaboration with other entities (not on their own) and prefer it this way. Some do not engage in outreach but would like to if their resources were expanded to make it feasible. Some commented that they used to engage in outreach but have had to cut back due to resource and staffing constraint. Some engage in outreach regularly as part of their primary functions. And for a small number, their entity's purpose does not align with outreach.

Outreach has been in the form of community awareness campaigns, providing trainings, and hosting informational booths at events. Stakeholders expressed a variety of entities and populations they would like to extend outreach to including nonprofits, churches, businesses, police, probation and parole, underserved or underrepresented communities (immigrant, refugee, indigenous), and victim services.

Focal Areas for Outreach Community Education/Awareness

Stakeholders had numerous suggestions for topical areas where they view a need for community education/outreach. Some recommendations are focused on outreach to disability populations specifically, others are applicable to the general public, and some are directed at specific professions. We combined these suggestions into three themes (see Figure 12).

Stakeholders pointed to a need for community awareness and education related to **ANE among persons with disabilities**, with some outreach needed for disability populations specifically and some outreach to the public. For example,

Figure 12. Areas for Outreach & Community Education

one stakeholder described a need for education on consent and self-confidence among persons with disabilities to aid in awareness and prevention. In terms of the general public (including persons with disabilities), stakeholders described a desire for better understanding and awareness of ANE among vulnerable adults: "*I wish they knew how often it really occurred, and I wish they knew how serious some of the situations were, or how serious some of the abuse is*" (Stakeholder 3). General community awareness is seen as especially important for aiding in identifying victimization experienced by people who do not use speech for communication or have other communication barriers to self-reporting.

A few stakeholders spoke to the importance of better awareness and education among persons without disabilities about living with disabilities. Myths and stereotypes surrounding disability can contribute to victimization and be used to the advantage of those looking to exploit or victimize others. One topical area in this regard is related to sterotypes about sexuality and disability. A stakeholder explained that stereotypes about persons with disabilities not being sexually active – or being sexually desireable - lead to them not being believed when they report sexual violence or when sexual abuse is determined to have occurred.

The majority of stakeholders reference that they wished people knew more about who they are, what they do, what services they provide, and what their authority is. Stakeholders expressed wanting to engage in outreach to raise community **awareness about their services**. Some stakeholders recognize this as a need in conjunction with low reporting: if more people knew about their services there would be more reports of ANE. Others recognize it because clients say things like "*this whole time I never knew you existed!*" (Stakeholder 7). Another stakeholder pointed out the connection between education and awareness, describing the negative effects of self-blame (or 'victim-blaming') – a common focus of community education for certain types of vicitmization generally – the need to connect with others to combat self-blame, and rasing awareness of services available for that purpose. Stakeholders highlight the potential benefits for creative thinking and collaborating around raising awareness across disbility and vicitmization services.

Several stakeholders indicated other **professional** arenas that they engage with where they see a need for increased awareness or education. These include making sure healthcare staff (doctors, nurses, physical therapists) are familiar with signs and

symptoms of ANE. Stakeholders indicated they have had experience with health care providers who did not seem to have the background knowledge to do this effectively, and others indicated that these professionals are sometimes the only outside persons an individual may come into contact with aside from their abuser, and thus they play a crucial role in identifying hidden ANE. Mental health care also received focus from stakeholders who want education and understanding of the intersection of mental health and disability. Finally, several stakeholders, many of those who provide vicitmization services in some capacity, identified a need for raising awareness about the intersection of disability and specific forms of victimization (domestic violence, elder abuse, sexual violence, trafficking, exploitation). This included suggestions for reviewing risk assessment tools and potentially developing additional assessment tools to aid with investigations and interviewing of potential victims.

Recommendations

The following recommendations are based on the findings in this report, including those recommendations made by stakeholders directly.

Recommendation 1: Expand community education, awareness, and prevention efforts.

Expansion may include consideration of resources, training, and public education, as well as methods of effective intervention. Increased awareness should focus on information related to identifying and reporting victimization for those with disabilities, as well as risk of victimization. Additionally, greater awareness of the intersection between disability, various forms of victimization, and other social issues is needed. For example, persons with disabilities are at heightened risk, not just for ANE by those closest to them, but for trafficking. There is also a need to focus on preventing offender behavior. As stakeholders pointed out, education and services to reduce caretaker stress may aid in preventing some ANE.

Recommendation 2: Enhance transparency surrounding decision-making and response procedures.

Stakeholders discussed disparities in accountability for caregivers who may have engaged in ANE. Caregivers or service providers who are found to have engaged in ANE in some settings (e.g., certified nursing assistants) are prohibited from future employment while those in other settings (e.g., assisted living facilities) are not. It is

recommended that restrictions for perpetrators of ANE are equalized across settings. Because of this, a review of statutes in coordination with discussions of accountability and risk reduction is recommended. This may include a registry for those found to be in violation of rights of individuals with disabilities, regardless of the type of service or care provided. As one stakeholder pointed out, other professions have review boards (board of nursing, board of medicine) and examining the feasibility of this type of structure in concert with a registry may balance accountability and due process.

Recommendation 3: Examine the current structure, responses, and accountability measures to identify gaps.

There are multiple entities that have the authority to investigate ANE among vulnerable adults. Reviewing the existing structure in the context of efficiency, clarity, and accountability may increase effectiveness in case processing. The current reporting system is multifaceted and often involves multiple entities. Multi-agency engagement (where not already happening systematically) can be pursued as an avenue for enhancing collaboration, resource sharing, and developing consistent policies and procedures. For example, one gap noted by stakeholders is "closing the information loop" with relevant parties whenever possible. Examining current structure and responses can be used to identify ways to improve this form of accountability.

Recommendation 4: Create opportunities for collaboration, networking, and cross-training between entities that are providing disability and victimization services.

Stakeholders providing disability services and stakeholders providing victim services expressed a desire for better engagement or interactions with other service providers, a desire to better understand what other providers do (or have other providers better understand what they do), a desire to develop comprehensive lists/contacts of service providers, and/or engage in relevant trainings with other entities. Additionally, some stakeholders indicated that networking and training with police would be beneficial to investigations. Assistance in coordinating and funding these types of opportunities would be needed.

Recommendation 5: Reduce barriers to reporting ANE and other forms of victimization.

Currently there are numerous entities to whom victims with disabilities could report. Unfortunately, it is often unclear who to report to and in what order. Centralizing information, resources, and points-of-contact for persons with disabilities may be one

avenue to consider as a means of reducing reporting burden. Minnesota's Disability Hub[vii] is an example of this type of model. This model can also assist persons with disabilities in navigating various systems (the criminal justice system, the healthcare system, what to expect after reporting). In addition to Minnesota other states have engaged in efforts to make reporting easier: Oregon and Missouri created detailed reporting guides, Pennsylvania passed state-mandated reporting legislation, and Florida maintains a single-number hotline for victims with disabilities to report. As one Idaho stakeholder put it, a "victim-centered approach" may reduce barriers to reporting and accessing services.

Given the role of fear in underreporting, systemic change may need to occur to ensure that reporting does not lead to negative or unintended consequences for victims. Combined with this, exploring options for increasing trust in the reporting process may be beneficial. One stakeholder suggested developing a peer-counseling or peer-guided reporting program.

Recommendation 6: Enhance accessibility of victim services and mental and behavioral health care.

Stakeholders providing victim services are aware that services need to be more accessible, as well as identifying needed services that they have not found in the community (for example, specialized support groups). To enhance accessibility, providers need training, resources, or to make connections with providers who can fill those accessibility gaps.

Several stakeholders pointed to the need for enhanced services at the intersection of disability and mental health, and that for those with and without dual diagnoses, finding counselors who are effective at working with trauma and disability is challenging. Further examination of the extent of these issues is needed to determine the best solutions. For example, exploring what nursing programs have done to respond to registered nurse shortages could be an option for trying to address specialized counselor shortages.

[vii] https://disabilityhubmn.org/

Recommendation 7: The state should examine opportunities for increasing investment in disability services.

More than one-quarter of the state's population is living with a disability, and this population is at an increased risk for victimization. At the same time, there is a current shortage of staff and resources needed to adequately serve this population, particularly in the context of ANE. Stakeholders referenced beneficial legislative engagement in the past, and even more stakeholders indicated a desire for legislators and policy makers to be engaged on this issue moving forward. This may include support for training, networking, and identifying systemic gaps.

Recommendation 8: Further evaluation of barriers and measures for improvement in serving victims from traditionally underserved populations is needed.

There appear to be issues specific to traditionally underserved populations who are also living with disabilities. Persons with disabilities who are immigrants, refugees, and without English fluency face additional burdens to reporting victimization and accessing services. More information is needed about these experiences and how to reduce burdens or resource gaps relating to effectively serving these groups.

Recommendation 9: Identify what is working well and expand on successes.

All stakeholders identified things that were working well relating to ANE response, serving clients, and/or engaging with the community or other entities. Things that professional stakeholders identify as working well should be compared with additional future research on what is working well from the perspective of persons with disabilities and other disability stakeholders. Through this process, promising practices can be identified and evaluated. Successful practices may be shared and replicated in other areas or with other entities.

Conclusion

Stakeholders are aware of many challenges facing their entities and facing persons with disabilities. These challenges are exacerbated by lack of funding, staff shortages, lack of other resources, and disconnection between (and among) various disability and victim service providers. Additionally, barriers to the identification and reporting of victimization need to be addressed. Policies and practices that mindfully serve victims without undue consequences, ensure accountability, and maintain due process should be considered. In doing so, victims are likely to benefit from the protections and services available. Facilitating and resourcing opportunities for professional stakeholders and other stakeholder groups to engage in open dialogue working towards a common purpose (and tangible solutions) can lead to better experiences and outcomes for persons with disabilities and those serving them.

End Notes

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