

JANUARY 2021

SEXUAL VIOLENCE/ABUSE AGAINST INDIVIDUALS
WITH INTELLECTUAL AND DEVELOPMENTAL
DISABILITIES

SUMMARY OF BEST PRACTICES AND LIVED EXPERIENCES IN ARIZONA

This design brings quantitative data (from a day treatment and group home provider survey) and qualitative data (interviews, focus groups, and document review) alongside best practice recommendations found in peer-reviewed literature to **highlight gaps in the current system and make recommendations for improvement** related to the detection, reporting, tracking, monitoring, and prevention of, as well as training, related to sexual violence committed against individuals with I/DD.

PRESENTATION OF FINDINGS

Due to the expansive nature of this research project, findings and recommendations are presented in two ways. First, in this comprehensive document, the detailed methods and findings of each of the three study strands of this research study are laid out. These sections include:

- **State of the Research**, a comprehensive literature review that reports the best practices associated with the detection, reporting, tracking, monitoring, and prevention of as well as training related to sexual violence/abuse committed against individuals with I/DD.

- **State of Providers**, a report of current practice as explained by day-treatment and group home providers across the state of Arizona.

- **Lived Experience**, a report that provides in depth accounts of the experiences and perspectives of individuals with I/DD, their caregivers (family members and legal guardians), law enforcement officers and Family Advocacy Center representatives.

Second, a **summary and recommendations** report entitled **Sexual Violence Against Individuals with I/DD: A Summary of Findings in Arizona**, provides an overview and synopsis of the work completed as well as a set of specific findings and recommendations from across all study strands. These reports can be assessed via the ADDPC website at www.addpc.az.gov. Questions related to this project can be addressed to ADDPC at <https://addpc.az.gov/about/contact-us> or directly to the research team at info@improvementassurance.com.

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STATE OF THE RESEARCH

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Literature Review

SEXUAL VIOLENCE/ABUSE AGAINST INDIVIDUALS WITH I/DD

STATE OF THE RESEARCH

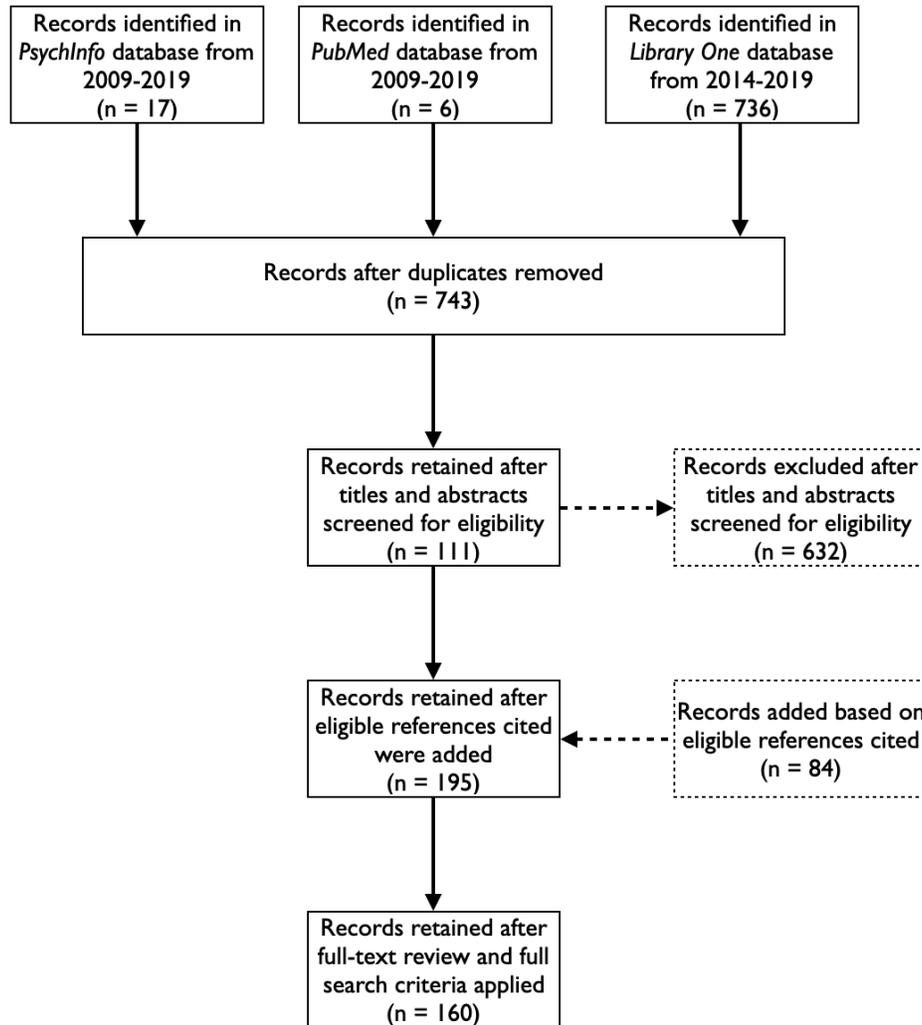
Sexual violence/abuse is a pervasive public health issue that disproportionately affects women, racial and ethnic minorities, and individuals with disabilities (Barger, Wacker, Macy, & Parish, 2009; Black et al., 2011). Current data by the Centers for Disease Control and Prevention (CDC) indicate that about one out of three women experience some form of sexual violence/abuse during their lifetime – about twice the rate of men (Smith et al., 2017). Individuals with intellectual and developmental disabilities (I/DD) are at an even greater risk of becoming victims of sexual violence/abuse than individuals without disabilities. Bureau of Justice data indicate that the rate of rape and sexual assault against individuals with intellectual disabilities is more than **seven times** the rate against individuals without disabilities. Among women with intellectual disabilities the rate increases to about **12 times** the rate against women without intellectual disabilities. Behind these numbers are children and adults who, as subsequent survivors of sexual violence/abuse, experience a wide range of long-term physiological and/or psychological health problems including symptoms of depression, anxiety, social isolation, and suicidal ideation (Murphy et al., 2007; Sequeira et al., 2003). While the personal suffering from sexual violence/abuse remains immeasurable, its financial consequences affect the public health system more than any other crime, resulting in an estimated economic burden of nearly \$3.1 trillion for rape alone (Peterson, DeGue, Florence, & Lokey, 2017).

Researchers conducted the present literature review to summarize current findings published in peer-reviewed literature over the last 10 years related to the (a) detection; (b)



reporting; (c) tracking; (d) monitoring; (e) training; and (f) prevention of sexual violence/abuse against children and adults with I/DD. While all research continues to evolve, this current state of the research provides insight into what is presently known and the extent to which any implications for practice are warranted. To ensure a methodical and replicable review, search methods and review sequence were conducted following recommended PRISMA guidelines (Moher, Liberati, Tetzlaff, & Altman, 2009). **Eligibility criteria** included: (a) original peer-reviewed studies published between 2009 and 2019; and (b) key word matches for any field inclusive of titles and abstracts based on “sexual violence abuse” and “intellectual developmental disabilities.” Eligible literature was located using the *PsycINFO* and *PubMed* databases. The resulting record number was low ($n = 23$), which prompted the inclusion of an additional database. *Library One* includes the full catalog of Arizona State University, which covers over 500 journal outlets. The review sequence and resulting records are detailed in **Figure 1**.

Figure 1. PRISMA flow diagram of the article selection sequence and resulting records



The use of the *Library One* database resulted in several thousand records based on the previous 10 years of research. To exclude out-of-date articles, the *Library One* search was subsequently limited to the last five years of research. After the removal of duplicates, a total of 743 records were identified. The titles and abstracts of this first set of records were examined based on the following exclusion criteria: (a) research conducted outside the United States, Canada, England, or Australia; (b) research focused on individuals with I/DD as offenders/perpetrators of sexual violence/abuse, (c) research

focused on the sexual expression of individuals with I/DD. The resulting set of records was comprised of 111 articles. Researchers reviewed the literature section for these articles and identified an additional set of records, which were included based on the citation's relevance to the topic of sexual violence/abuse against individuals with I/DD. After the removal of duplicates, a total of 84 records were added to the previous 111 records. From there, two independent reviewers conducted a full-text review of each of the 195 records with a refined set of inclusion criteria based on the journal article's contribution to one or more of the following categories: (a) detection; (b) reporting; (c) tracking; (d) monitoring; (e) training; and (f) prevention of sexual violence/abuse against individuals with I/DD. After that review was complete, two additional expert reviewers conducted a second full-text review of all 195 records to confirm the previous reviewers' selection, resolve any discrepancy, and summarize the final selection in a review table. Expert reviewers had to resolve 37 discrepancies between the two reviews. The final set of unique records retained for inclusion in the review table and synthesis of results included a total of 160 peer-reviewed journal articles published between 1992 and 2019.

The current literature does not provide consistent definitions for each of these six categories, so we have provided definitions in **Table 1**. A critical issue related to all six categories is the prevalence of sexual/violence abuse against individuals with I/DD. Understanding what available prevalence data suggest is important, because a higher risk for sexual violence/abuse against individuals with I/DD compared to against individuals without disabilities would suggest the need for separate and distinct actions or processes of detection, reporting, tracking, monitoring, training, and prevention. In addition, prevalence data might be able to identify differential risk for specific subgroups of individuals with I/DD. As such, we begin our review by summarizing prevalence estimates for children with disabilities, adults with disabilities, and subsequently any subgroups within each of the two.

Table 1. *Definition of Categories*

CATEGORY	DEFINITION
Detection	The action or process of identifying the risk for, or the presence of, sexual violence/abuse against individuals with I/DD. For example, screeners and risk assessment, as well as investigations of allegations of sexual violence/abuse perpetrated against individuals with I/DD.
Reporting	The action or process of disclosing to others an experience of sexual violence/abuse. For example, self-report or reporting by others to law enforcement, formal authorities, caregivers, peers, and others.
Tracking	The action or process of recording data on allegations of sexual violence/abuse perpetrated against individuals with I/DD and its outcomes. For example, electronic databases or registries for recording cases of sexual violence/abuse investigations against individuals with I/DD and its outcomes.
Monitoring	The action or process of ongoing oversight, typically by an authoritative body, to ensure established policies and procedures are effectively implemented and enforced. For example, federal and state statutes for prevention, tracking, training, and mandatory reporting of sexual violence/abuse against individuals with I/DD.
Training	The action or process of providing individuals with I/DD or those who interact with them the knowledge and skills to prevent, detect, and report sexual violence/abuse against individuals with I/DD.
Prevention	The action or process of stopping sexual violence/abuse against individuals with I/DD before it occurs. For example, programs, trainings, or curricula to reduce or eliminate sexual violence/abuse against individuals with I/DD.

PREVALENCE

Data on the prevalence of sexual violence/abuse against individuals with I/DD are not easily summarized, due to differences in how victimization and disability are defined and disaggregated across various data sources. Victimization may be reported as neglect, maltreatment, emotional abuse, physical violence/abuse, or sexual violence/abuse. Disability may be reported as mental/intellectual, developmental, or physical. Additional intersections may also be reported including gender (i.e., male, female) and age (i.e., children, adults, elderly).

Current data from the Bureau of Justice Statistics' *National Crime Victimization Survey* (2017) provided general information about crime against individuals with disabilities (age 12 or older). Based on 2015 data, the rate of violent victimization against individuals with disabilities was **2.5 times higher** than the rate for individuals without disabilities. The Bureau of Justice classified disabilities based on six limitations:

- hearing (deafness or serious difficulty hearing);
- vision (blindness or serious difficulty seeing, even when wearing glasses);
- cognitive (serious difficulty concentrating, remembering, or making decisions because of a physical, mental, or emotional condition);
- ambulatory (difficulty walking or climbing stairs);
- self-care (a condition that causes difficulty dressing or bathing);
- independent living (physical, mental, or emotional condition that impedes doing errands alone, such as visiting a doctor or shopping).

Violent victimization included simple assault as well as serious violent crime (i.e., rape/sexual assault, robbery, aggravated assault). For rape/sexual assault, the rate of violent victimization against individuals with disabilities was **3.5 times higher** than the rate against individuals without disabilities. Among the six disability types measured, the rate of violent victimization was the highest for **individuals with cognitive disabilities**. No statistically significant difference was found for gender in the rate of violent victimization. Among those with disabilities, **younger individuals** (ages 12 to 15) had the highest rate of violent victimization among all age groups measured. The majority (65%) of rapes or sexual assaults against individuals with disabilities were committed against **individuals with multiple disabilities**.

It is noteworthy that unpublished data from the Bureau of Justice Statistics' *National Crime Victimization Survey* (2011-2015) obtained by Katie Park for a National Public Radio (NPR) special series (<https://www.npr.org/series/575502633/abused-and-betrayed>) confirmed that individuals with intellectual disabilities represent a particularly vulnerable disability group. The rate of rape and sexual assault against individuals without disabilities was about 0.5 per 1,000 people. The rate against individuals with disabilities the rate increased to 2.1 per 1,000 people. The rate against individuals with intellectual disabilities the rate increased even further to **4.4 per 1,000 people**. Moreover, gender was identified as a major risk factor. While the rate of rape and sexual assault against men with intellectual disabilities was about 1.4 per 1,000 people, the rate against women with intellectual disabilities increased to about **7.3 per 1,000 people**. As such, the rate of rape and sexual assault against individuals with intellectual disabilities is more than **seven times** the rate against individuals without disabilities. The rate against women with intellectual disabilities is about **12 times** the rate against individuals without disabilities.

A systematic review and meta-analysis of observational studies by Jones et al. (2012) provided estimates on the prevalence and risk of violence (i.e., physical, sexual, emotional, neglect) perpetrated against children with disabilities (i.e., mental/intellectual, physical). Based on the pooled risk estimates for all four types of violence, the findings established that "children with disabilities are at a significantly greater risk of violence than are their peers without disabilities" (Jones et al., 2012, p. 904). Moreover, children with mental/intellectual disabilities have a higher prevalence and risk of violence than children with other disability types, especially for the prevalence of physical violence and emotional abuse and for the risk of sexual violence. For children with a mental or intellectual disability, the results indicated a **pooled prevalence estimate of 15% for sexual violence** based on eight studies with a 95% confidence interval indicating a range between 7.1% and 24.0%. The pooled odds ratio for sexual violence against children with a mental or intellectual disability based on four studies was 4.6 with a 95% CI indicating a range between 2.1 and 10.2. As such, the findings indicated that the odds of being a victim for sexual violence was **4.6 times higher for children with a mental or intellectual disability** compared to controls (i.e., general population).

In a similar study on adults with disabilities (Hughes et al., 2012), the results indicated a **pooled prevalence estimate of 5.5% for sexual violence** based on six studies with a 95% CI indicating a range between 1.3% and 22.3%. Unfortunately, the findings were not specific to adults with mental/intellectual disabilities. The pooled odds ratio for

violence against adults with an intellectual disability based on three studies was 1.6 with a 95% CI indicating a range between 1.1 and 2.5. Unfortunately, the findings were not specific to sexual violence.

A study conducted by Mitra et al. (2011) focused on sexual violence/abuse against adult men with disabilities and indicated that, even after controlling for sociodemographic characteristics, men with disabilities were **more than 4 times** as likely to report lifetime and past-year victimization than men without disabilities. In fact, the prevalences of lifetime sexual violence, completed rape, and attempted rape against men with disabilities were comparable to those against women without disabilities (Mitra et al., 2011).

In summary, the available research on prevalence permits several conclusions. First, a strong body of research has established significantly different prevalence estimates of sexual violence/abuse against individuals with disabilities compared to individuals without disabilities. Simply having a disability—irrespective of age, gender, or type of disability—more than doubles the risk of becoming a victim of sexual violence/abuse compared to someone who does not have a disability. As such, individuals with disabilities constitute a uniquely vulnerable group that requires **separate and distinct actions and processes** of detection, reporting, tracking, monitoring, training, and prevention of sexual violence/abuse. Second, the research literature further affirms that individuals with disabilities are a very heterogenous group comprised of different risk profiles. Based on the available literature, three major intersectionalities compound the risk for sexual violence/abuse of individuals with disabilities: (a) age, (b) gender, and (c) disability type(s). Specifically, younger individuals with disabilities, female individuals with disabilities, and individuals with intellectual and/or multiple disabilities face an increased risk. These elevated risk profiles require **additional amendments** to any existing actions and processes concerning individuals with disabilities. While more research is needed, available research suggests that multiple combined intersectionalities can compound an individual's risk. For example, females with intellectual disabilities experience rape and sexual assault at 12 times the rate of individuals without disabilities. As more research is being conducted, it is important to err on the side of caution and safeguard vulnerable populations.

"It is shocking that children with ID are at a significantly increased risk of maltreatment, and this obviously calls for preventive and early intervention actions."

Dion et al., 2018, p. 185

DETECTION

The category of detection is defined as the action or process of identifying the risk for, the presence of, or investigations of sexual violence/abuse against individuals with I/DD. A review of the literature that met inclusion criteria for this category resulted in a total of 31 relevant articles published between 1995 and 2018 with the majority of articles (58%) published between 2012 and 2018.

KEY THEMES

Key themes noted in the literature ($n = 31$) addressed the (a) identification of risk factors (i.e., factors associated with a higher risk for sexual violence/abuse); (b) screening or measurement of sexual violence/abuse; and (c) potential issues during investigations of allegations (e.g., interrogative suggestibility of individuals with I/DD).

RISK FACTORS. Research findings on risk data are largely congruent with previously discussed data on prevalence. As noted, disability status is the first dichotomous risk factor, placing all individuals with disabilities at an elevated risk for sexual violence/abuse. Once identified with a disability, an individual can accumulate additional risk factors based on personal and contextual characteristics. Based on the available literature, three broad categories of **personal characteristics** can be established: (a) age, (b) gender, and (c) disability type(s). Depending on the study, disability type specifies what kind of impairment/disability an individual is diagnosed with and/or receives services for (e.g., mental/cognitive/intellectual disability, physical disability). Individuals with disabilities who are younger, female, and/or have an intellectual disability are all subject to a higher risk. Some researchers further noted elevated risk due to having multiple disabilities (i.e., increased intensity of needs); exhibiting aggressive, violent, and/or other non-compliant behaviors; as well as having no regular visitors (Kamavarapu et al., 2017).

Contextual characteristics that further increase risk include (a) presence of interpersonal/domestic violence among parents and/or caregivers and (b) instability of parents and/or caregivers (Corr & Santos, 2017). Frequent changes in housing and/or caregivers represent a major contextual risk factor. Other contextual risk factors include

the following **parent/caregiver** characteristics: (a) use of illegal drugs, (b) use of homeless shelters, (c) low educational attainment, (d) teen pregnancy, (e) four or more children, (f) receipt of child or income support, (g) low socioeconomic status; and (h) high levels of stress (Casanueva et al., 2008). Contextual risk factors related to **staff** included having largely male, non-trained frontline care staff. Hawaii's *Healthy Start Program*, for example, includes a population-based risk assessment that screens families of newborns for high risk of abusive situations based on 15 areas: (a) parents not married; (b) unemployed partner; (c) inadequate income; (d) unstable housing; (e) lack of telephone; (f) less than a high school education; (g) inadequate emergency contacts; (h) marital or family problems; (i) history of abortions; (j) abortion unsuccessfully sought; (k) history of substance abuse; (l) history of psychiatric care; (m) history of depression; and (n) inadequate prenatal care (Duggan et al., 1999).

Kamavarapu and colleagues (2017) identified **facility** risk factors as (a) lack of proactive reporting structure (i.e., victim would be required to report abuse); (b) unsupervised personal and/or medical care situations (e.g., taking a shower, placing a catheter); (c) ineffective staff supervision; and (d) lack of policies and procedures that address sexual violence/abuse.

In terms of establishing these risk factors, Hibbard and colleagues (2007) identified pediatricians as playing a key role in identifying the risk for, or the presence of, sexual violence/abuse against individuals with I/DD. With regular well-child visits for younger children, pediatricians as a group have a unique opportunity to be in regular contact with children in their community. However, Hibbard and colleagues acknowledge that "signs and symptoms of maltreatment in children with disabilities are commonly ignored, misinterpreted, or misunderstood" (p. 1019). As such, even pediatricians would need specialized training and/or access to appropriate screening options.

To synthesize risk factors, we recommend application of the integrated **ecological model of abuse** (Sobsey, 1994), which highlights the interactions between four systems: (a) the potential victim, (b) the potential offender, (c) the immediate environment, and (d) the culture. For example, a young girl with I/DD (potential victim) who is dependent on a highly stressed, male caregiver with little training (potential offender) and lives in an isolated group home (environment) with a cultural context that devalues people with disabilities (culture) would be at high risk for abuse.

SCREENING OR MEASUREMENT. The high prevalence of sexual violence/abuse against individuals with disabilities “confirms the need for universal screening for abuse during every client contact in rehabilitation, health-care, and other professional settings” (Hassouneh-Phillips & Curry, 2002, p. 102). Unfortunately, the research literature presently does not provide a meta-analytic review of available screeners and related measures. However, the literature base for this review included several instruments that can be used for purposes of detection.

Atkinson and Ward (2012) developed an assessment to measure incidents of **interpersonal violence against individuals with I/DD** called the *Interpersonal Violence Interview* (IVI). The IVI is a 30-question, semi-structured interview to solicit information about incidents of interpersonal violence over a specified time period. For the development of the IVI, Atkinson and Ward used the World Health Organization’s definition of intimate partner violence to describe behaviors that cause physical, psychological, or sexual harm. As such, the IVI addresses a variety of systematic abusive behavior including threats and acts of physical violence, sexual violence, emotionally abusive behaviors, economic restrictions, and other controlling behaviors. In practice, the IVI requires a clinician who uses its 30 interview questions to ask individuals with I/DD about incidents of interpersonal violence based on a specified timeframe (e.g., since your last birthday). The response choices are *yes*, *no*, *don’t know*, *refused to answer*, or *not applicable*. The psychometric evidence presented in Atkinson and Ward (2012) was limited to content validity, inter-rater reliability, and test-retest reliability. Accessibility for children and adults with I/DD during the interview process was not addressed.

Berstein et al. (2003) developed a brief screening version of the *Childhood Trauma Questionnaire* (CTQ), which was originally a 70-item self-administered inventory designed to assess a broad range of **maltreatment experiences** (i.e., physical and emotional abuse, emotional neglect, sexual abuse, and physical neglect). The short form of the CTQ consists of 28 Likert-type items and requires about five minutes to self-administer. Results provided strong psychometric support for the coherence and viability of the constructs measured by the CTQ-SF, including the invariance of its factor structure across diverse populations and its criterion-related validity in an adolescent psychiatric population. The accessibility of the CTQ-SF items for children and adults with I/DD was not addressed.

Fisher, Moskowitz, and Hodapp (2012) developed the *Social Vulnerability Questionnaire* (SVQ), which is designed to be used by an interviewer who rates an individual with I/DD on 30 Likert-type items (1=*not true or never* to 4=*very true or always*) and asks one open-ended question. The questions were derived from existing measures

of bullying, gullibility, abuse, and elder deception. Psychometric evidence included factor analysis in support of six factors (**emotional bullying, risk awareness, social protection, perceived vulnerability, parental independence, credulity**), internal reliability, and factor means. The study by Fisher et al. (2012) showed the scores on each of these six factors were related to various demographic and behavioral characteristics. As such, the SVQ can be used to assess potential risk of social victimization for individuals with I/DD. Scores on this measure can be used, along with other characteristics of the individual, to determine if the individual is at risk for victimization or has greater potential to avoid victimization.

McFarlane and colleagues (2001) developed the *Abuse Assessment Screen-Disability* (AAS-D), which is a four-question screening instrument designed to be completed by an interviewer who records the **presence (yes/no) of abuse**, possible perpetrator (e.g., intimate partner, care provider), and additional details through open-ended responses. Psychometric evidence is largely based on previously established reliability and concurrent validity of the AAS. Moreover, the utility of the measure is limited since individuals with cognitive or communication impairments would be unable to accurately respond to the questions during the interview.

While it is possible to adapt existing measures for use by individuals with disabilities through community-based participatory research (Nicolaidis et al., 2015), **audio computer-assisted self-interviews** (ACASIs) are recommended for use with individuals with disabilities (Oschwald et al., 2014). Using ACASIs allows for the collection of anonymous information directly from the individual (self-report) without the presence of an interviewer. Compared to paper questionnaires and face-to-face interviews, ACASIs provide higher rates of disclosure of sensitive information (e.g., Renker, 2008; Turner et al., 1998). In addition, the ACASI can provide accessibility accommodations for individuals with a variety of disabilities including embedded audio and/or visual media, changes in font size, visual tracking cues, enhanced keyboards, and screen-reader functionality. A carefully designed ACASI can remove participation barriers, increase privacy and anonymity, and decrease the need for proxy reporting (i.e., interviewers).

INVESTIGATION OF ALLEGATIONS. To substantiate an allegation of sexual violence/abuse, law enforcement will typically suggest a forensic interview. Newlin et al. (2015) defined a forensic interview of a child as “a developmentally sensitive and legally sound method of gathering factual information regarding allegations of abuse or exposure to violence [...] conducted by a competently trained, neutral professional

utilizing research and practice-informed techniques as part of a larger investigative process” (p. 3). Best practices suggest four major considerations when conducting the forensic interview: (a) age and developmental abilities; (b) cultural differences; (c) disabilities; and (d) trauma (Newlin et al., 2015). For individuals with disabilities, best practice recommendations include the need for collaboration between the forensic interviewer and a **disability specialist** or other professional who works with children of a given disability and their caregivers. Such a collaboration is almost always necessary, given the complexities of disabilities and the extent to which they require special accommodations during the interview process (Baladerian, 1997; Hershkowitz, Lamb, & Horowitz, 2007; Faller, Cordisco Steele, & Nelson-Gardell, 2010).



KEY FINDINGS

Based on the available literature, the following recommendations should be considered to improve the detection of sexual violence/abuse against individuals with I/DD.

- ✓ Establish policies and procedures related to sexual violence/abuse that specifically address individuals with disabilities **[1.1]**
- ✓ Provide additional policy and procedural safeguards that address children with disabilities, women with disabilities, and individuals with I/DD and other cognitive impairments **[1.2]**
- ✓ Administer risk assessments for sexual violence/abuse in facilities that serve individuals with disabilities that determine risk level based on intersectionalities related to personal characteristics including age, gender, and disability type(s); and contextual characteristics of the parent/caregiver, staff, and facility **[1.3]**
- ✓ Administer universal screening assessments in facilities that serve individuals with disabilities with options for audio computer-assisted self-interviews (ACASIs) **[1.4]**
- ✓ Train forensic interviewers on techniques that consider the effects of age and developmental abilities; cultural differences; disabilities; and trauma **[1.5]**
- ✓ Ensure the availability of a disability specialist during forensic interviews **[1.6]**

REPORTING

The category of reporting is defined as the action or process of disclosing an experience of sexual violence/abuse to another person — whether that’s self-reporting or reporting by others to law enforcement, formal authorities, caregivers, peers, or others. Reporting of sexual assault is a crucial first step in addressing the trauma experienced by victims and pursuing justice. The barriers and stresses associated with reporting sexual assault are well documented and include feelings of shame and embarrassment and re-living the trauma by having to report it (Sable et al., 2006). However, individuals with I/DD experience more and different kinds of barriers to reporting incidents of sexual violence/abuse than other individuals. A review of the literature that met inclusion criteria for this category resulted in a total of 26 relevant articles published between 1999 and 2018 with the majority of articles (50%) published between 2011 and 2018.

KEY THEMES

Key themes noted in the literature ($n = 26$) addressed (a) challenges with communication of incidents to authorities; (b) fear of consequences as a result of reporting incidents; (c) lack of sexual health knowledge and related education among individuals with I/DD; (d) lack of awareness of a right to be safe and free from abuse; and (e) power imbalances experienced by many individuals with I/DD.

COMMUNICATION. Multiple articles mentioned difficulties with communication as a significant barrier for individuals with I/DD reporting sexual violence/abuse. The **ability to verbalize** what happened during a sexual assault incident is critical to reporting, identifying the perpetrator, and receiving appropriate trauma support. Several qualitative studies documented challenges regarding verbal accounts experienced by both victims and investigators. For example, one survivor reported difficulties providing an account due to being continuously interrupted and one interviewer reported the need to abandon the interview because of frequently changing details (McGilloway et al., 2018).

One study found that **verbal intelligence** scores were closely related to voluntary disclosure of sexual assault. In fact, verbal intelligence was a stronger predictor of reporting than age at interview, relationship to the perpetrator, multiple episodes of abuse, type of sex abuse, or more than one perpetrator being involved in the abuse (Bae et al., 2017). Due to these challenges and reduced likelihood of voluntary reporting among sexual assault victims with I/DD, recommendations have been proposed in the literature that questionnaires be developed and administered to uncover whether a person has an abuse history (McFarlane et al., 2001).

Researchers have further noted significant obstacles for sexual assault victims with I/DD related to the investigative and prosecutorial aspects of reporting. As noted by Antaki et al. (2015), individuals with I/DD experience difficulties when required to **access memory** and respond to **complex or tendentious questions**, which are commonplace in the justice system. Tendentious questions are questions that are intentionally biased to test the integrity and consistency of witness statements during police interrogations or forensic interviews. Studies have found that it is more difficult for individuals with I/DD to identify and refute statements that imply blame on the part of the victim (Antaki et al., 2015). In addition, studies have found that individuals with I/DD are more likely to acquiesce to statements they don't agree with than the general population (Bowden et al., 2014).

Multiple studies reported concerns with the traditional justice system process, as it typically lacks accommodations for individuals with I/DD (e.g., Antaki et al., 2015; Bowden et al., 2014; Milne et al., 2002). For example, traditional **cross-examination practices** have been identified as problematic for individuals with I/DD. Attorneys can be aggressive and induce stress in witnesses, which has been shown to impair their memory. In fact, Bowden et al. (2014) indicated that a **reduction of stress** for the victim can improve accuracy and completeness of testimony for people with I/DD. Other issues with cross-examination mentioned in literature were the use of (a) complex or confusing questions, (b) double negatives, and (c) overt focus on discrediting witness statements (Bowden et al., 2014). Points were also made about the stress and trauma associated with providing **live testimony** in a court and a judge's lack of willingness to intervene in a line of questioning for fear of jeopardizing a defendant's right to a fair trial and potentially having their judgement be overturned in appeal (Bowden et al., 2014).

To counteract some of the difficulties with the traditional justice system process, several recommendations were noted in the literature. Multiple researchers advocated for greater training of police departments, judges, and lawyers regarding the capacity of

individuals with I/DD to communicate and the necessity for accommodations and additional support during the justice system process (Bowden et al., 2014; McGilloway et al., 2018). After a systematic review of different countries' approaches, Bowden et al. (2014) recommended that the best way to improve the trial process and quality of evidence is to **replace traditional cross-examination** practices with separate **investigative and evidential interviews** conducted by an **expert interviewer** with training specific to working with people with I/DD (see recommendations 1.5 and 1.6). Bowden et al. (2014) recommended that an investigative interview should (a) take place as soon as possible after the sexual assault, (b) use a properly trained interviewer (i.e., specialized knowledge regarding comprehension and communication difficulties common for individuals with I/DD), (c) include video recording to show facial expressions; and (d) avoid police officers conducting the questioning and interrogation. Moreover, lines of questioning should be submitted to the interviewer so that they may be adapted prior to being presented to the victim.

It should be noted that despite the aforementioned challenges, individuals with I/DD can provide descriptions of events that have happened to them provided they are asked questions appropriate to their comprehension level and are supported by a professional who has knowledge of communication and comprehension difficulties specific to individuals with I/DD.

FEAR OF CONSEQUENCES. Another reporting challenge identified in the literature was an individual's fear of what might happen as a result of reporting sexual violence/abuse. These fears are similar to the apprehensions experienced by all sexual assault victims regardless of whether a person has an I/DD or not. A substantial body of literature has established that sexual assault victims often fear that others will (a) doubt or discredit their accounts of what happened, (b) blame them for what happened, and/or (c) retaliate against them, especially if the perpetrator is known to them (e.g., McGilloway et al., 2018; Powers & Oswald, 2004).

A concern unique to individuals with I/DD is a person's fear of **losing their independence** after reporting an incident of sexual violence/abuse (McGilloway et al., 2018). For individuals with I/DD who have children, another fear is **loss of custody**. They are afraid their children will be removed, because authorities might think they are unable to protect their children (Powers & Oswald, 2004). Individuals with I/DD also expressed distinct fears around retribution from the perpetrator. Since a victim with I/DD may

depend on the perpetrator for basic daily needs or financial support, the opportunities for, and impact of, retribution are significant (McGilloway et al., 2018).

One author team noted that while most current resources go to training service providers to prevent and report sexual/violence abuse, more resources should be dedicated to **empowering individuals with I/DD** by providing them with the supports and tools necessary to recognize and report sexual violence/abuse. The tools mentioned included a wallet card with emergency phone numbers, a self-administered abuse screening tool, and ensuring that all people had access to a phone or alert button in their home that they can use independently at any time. (Powers & Oswald, 2004). Another recommendation cited in the literature is to train and communicate to individuals with I/DD that they have the right to be safe and that abuse is not the victim's fault nor is it a sign of incompetence (Powers & Oswald, 2004).

LACK OF SEXUAL HEALTH EDUCATION. A lack of sexual health education ("sex education") can disempower individuals with I/DD and contribute to challenges in differentiating acceptable from unacceptable behavior (Eastgate et al., 2011; Wacker et al., 2009). While some authors noted the general public may fear providing sex education will lead to sexual impulses that would have not presented themselves otherwise (Brown & Pirtle, 2008), several studies have demonstrated that sex education programs that are designed specifically to meet the needs of people with I/DD can increase the capacity of a person to make informed decisions about sexuality (Caspar & Glidden, 2001). The training and prevention sections of this review provide additional details on sex education.

LACK OF AWARENESS OF RIGHT TO BE SAFE. A few studies noted a lack of awareness among some individuals with I/DD that everyone has a right to be safe and free from harm. If an individual with I/DD is regularly exposed to a culture of abuse, including emotional and physical abuse, some authors provided reports that individuals with I/DD may accept abuse as part of daily life. Recommendations were made in the literature to educate individuals with I/DD about the right to be safe and increase their ability to recognize abuse in order to report it (Northway et al., 2014; McGilloway et al., 2018). The training section of this review provides additional details on sexual violence/abuse prevention trainings.

POWER IMBALANCES. Power imbalances in the lives of people with I/DD can also contribute to a reluctance in reporting sexual violence/abuse. As noted by Forde (1999), many individuals with I/DD who were the victims of sexual violence/abuse were dependent on their abusers for various **daily living activities** including eating, taking medicine, going to the bathroom, and showering. These dependencies can create opportunities for (a) sexual violence/abuse, (b) cover-ups by legitimizing inappropriate behavior; and (c) retaliation by making threats and/or withholding necessary activities (McGilloway et al., 2018). Another factor that can contribute to power imbalances is the common **expectation and reinforcement of compliance** by individuals with I/DD with caregiver tasks. Forde (1999), for example, provided accounts of individuals with I/DD wherein non-compliance led to a loss of privileges, while compliance was rewarded with access to entertainment. This culture of compliance is common and can compete with skills necessary to reduce vulnerability to abuse such as empowerment, autonomy, and recognizing the right to one's own body and boundaries (Forde, 1999; Martinello, 2014).



KEY FINDINGS

Based on the available literature, the following recommendations should be considered to improve the reporting of sexual violence/abuse against individuals with I/DD.

- ✓ Develop questionnaires, to be used by pediatricians, for routine screening of an individual with I/DD for potential abuse history as a means of reducing the burden of voluntary disclosure **[2.1]**
- ✓ Reform traditional justice system practices to better accommodate individuals with I/DD by having trained specialists conduct investigative and evidential interviews with victims, replacing cross-examination techniques while still ensuring a fair trial **[2.2]**
- ✓ Provide education and training to individuals with I/DD to create awareness of a right to be safe, avoid self-blame, and reduce fear of retaliatory consequences **[2.3]**
- ✓ Offer self-administered screening tools to ensure individuals with I/DD have a discreet way to self-disclose and offer other accessible means to

independently signal for help within provider facilities (e.g., emergency button) [2.4]

- ✓ Provide sex education to individuals with I/DD to empower them and decrease vulnerability [2.5]
- ✓ While task compliance may be necessary in some instances, clarify appropriate contingencies and reinforcement for compliance [2.6]

TRACKING

The category of tracking is defined as the action or process of recording data on allegations of sexual violence/abuse perpetrated against individuals with I/DD and their outcomes, such as electronic databases or registries. A review of the literature that met inclusion criteria for this category resulted in zero relevant articles published between 2009 and 2019. While no peer-reviewed articles were found, several **government reports** were noted during the literature review that addressed, at least in part, the issue of tracking. Two reports from the United States and one from Australia dealt with the issue of data collection and record keeping. Their findings are briefly discussed below.

KEY THEMES

While no peer-reviewed articles matched the inclusion criteria for tracking, a review of three governmental reports provided some insight on the topic. Given that numerous federal and state agencies are concerned with the welfare of its citizens, including individuals with disabilities, the efficiency and effectiveness of data collection and tracking efforts related to sexual violence/abuse hinge on (a) clearly defined and consistently applied terminology that describes the various types of sexual violence/abuse; (b) clearly defined and consistently applied terminology that describes the various types of disabilities; (c) established data management policies and procedures that include intra- and interagency information sharing.

In 2008, the Commission of Inquiry of South Australia published its final report of the *Children in State Care Commission of Inquiry*. For purposes of the inquiry, 792 people were identified as survivors of child sexual abuse while living in South Australia. The 406 males and 386 females made 1,592 allegations dating from the 1930s to 2004 against 1,733 alleged perpetrators. Thousands of records across various government and non-government agencies were requested and reviewed to collect data related to the alleged victims and their places of care at the time of the alleged abuse. Review of records included (a) institutional care; (b) smaller group care; (c) residential care ; (d) foster care; (e) family home; and (f) secure care. The nearly 600-page report included a section on maintaining adequate records. Based on 5,880 requested records, the findings indicated that many records were inadequate due to poor file management practices and minimal documentation. Subsequent legislative guidelines required **adequate records management** (ARM), which necessitates that records are created, captured, disposed of systematically, accessible, locatable, reliable, and managed. Guidelines further required that records management include policies, procedures, and practices, reporting mechanisms, and staff training. Other recommendations issued included extending the retention period of any records and files to 105 years and implementing an **electronic document and records management system** (EDRMS) for managing all paper and electronic client and administration files as well as file tracking.

In 2016, the United States Government Accountability Office (GAO) issued a Senate report on sexual violence data specifically addressing actions needed to improve the clarity of data across several data collection efforts by the Departments of Defense, Education, Health and Human Services, and Justice. One of the key findings by the GAO included the **inconsistent use of sexual violence terminology** across different agencies, which resulted in varying estimates of sexual violence. For example, agencies reported estimates for “rape or sexual assault victimization” as low as 244,190 but also reported “victims of rape or attempted rape” as high as 1,929,000. The GAO argued the lack of common terminology can lead to confusion for the public, undermining efforts to prevent, address, and understand the consequences of sexual violence. Key recommendations included (a) making information on the acts of sexual violence and contextual factors publicly available; and (b) creating an interagency forum on sexual violence statistics to review the appropriateness of varying terminology.

The third report that merits mentioning was published by the National Center for Injury Prevention and Control of the Centers for Disease Control and Prevention in 2014. The report, titled *“Sexual Violence Surveillance: Uniform Definitions and Recommended*

Data Elements, Version 2.0" (Basile et al., 2014), is relevant because it provided a variety of stakeholders with guidance for data collection efforts related to the public health surveillance of sexual violence. Public health surveillance refers to the ongoing, systematic collection, analysis, interpretation, and dissemination of data on health-related events. As such, the document was designed to promote and improve the consistency of sexual violence surveillance across organizations. Specifically, the report provided guidance on (a) uniform definitions for sexual violence; (b) data elements for record-based and survey surveillance of sexual violence; and (c) recommended data elements for sexual violence (i.e., identifying information, victim demographics, victim's first known incident of sexual violence, victim's most recent incident of sexual violence). Disability status of the victim was included in the recommended identifying information to be collected on the victim. A total of six codes were presented including deaf/difficulty hearing, blind/difficulty seeing, mental or emotional condition, physical condition, other, and unknown.



KEY FINDINGS

Based on the limited information available, the following findings for tracking sexual violence/abuse against individuals with I/DD can be noted.

- ✓ Tracking of sexual violence/abuse, including acts against individuals with I/DD, should occur on the basis of well-defined terminology that is used within and across all agencies involved in the welfare of individuals with I/DD **[3.1]**
- ✓ Terminology should define various types of sexual violence/abuse and disabilities **[3.2]**
- ✓ Guidance on definitions and additional data elements useful for tracking sexual violence/abuse is available by the *National Center for Injury Prevention and Control of the Centers for Disease Control and Prevention* **[3.3]**
- ✓ All agencies involved in tracking sexual violence/abuse and/or individuals with disabilities must have dedicated data management in place that includes policies, procedures, practices, reporting mechanisms, and staff training — and, ideally, these data systems should be centralized or able to cross reference with one another **[3.4]**

MONITORING

The category of monitoring is defined as the action or process of ongoing oversight, typically by an authoritative body, to ensure established policies and procedures are effectively implemented and enforced. Monitoring is essential to ensuring the safety of individuals with I/DD, as it represents a “key mechanism to help safeguard people from violence, exploitation, and abuse” (Laing, 2017). Article 16 of the *United Nations Convention on the Rights of Persons with Disabilities* (CRPD) specifies that every country must “ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.”

A review of the literature that met inclusion criteria for this category resulted in a total of four relevant articles published between 2010 and 2015. Of those four articles, only one was entirely focused on monitoring as outlined in Article 16 of the CRPD. Further, all four articles highlighted research and practices abroad: two in the UK (Laing, 2017 & Beadle-Brown et al., 2010) and two in Australia (Tucci et al., 2015 & Broadley, 2015). As such, the academic literature on monitoring sexual/violence abuse against individuals with I/DD is presently very limited, however a few key themes and recommendations should be noted.

KEY THEMES

At the time of this writing, the United States has not ratified the *Convention on the Rights of Persons with Disabilities* (CRPD). President Barack Obama signed the CRPD in 2009; however, it has not been ratified on both occasions it was presented to the United States Senate in 2012 and 2013. Cited as the first international treaty to address disability rights globally, Article 16 of the CRPD was selected as the basis for understanding a government’s monitoring obligations for purposes of this review. Its requirements and provisions have been widely applied across 129 countries that have ratified the treaty and are generally viewed as compatible with existing U.S. laws and policies including the

Americans with Disabilities Act (ADA) and the *Individuals with Disabilities Education Act* (Blanchfield & Brown, 2015).

Increased understanding of effective monitoring would disproportionately benefit individuals with I/DD residing in group homes or receiving support through day treatment programs. Individuals receiving care and treatment in these settings are two to four times more likely to experience sexual abuse than their peers residing in and/or receiving care outside of institutional settings (Sobsey et al., 1990). This increased risk makes individuals receiving care in institutional settings a particularly vulnerable population for whom additional safeguards ought to be put in place. Additionally, these settings most closely align with the facilities and programs described by Article 16. It states, "in order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities." Here, facilities and programs refer directly to care settings outside of the home. Allocation of funding as well as licensure for such organizations by the state poses an opportunity to exercise monitoring as part of compliance and eligibility requirements.

Leveraging what little is known at this time, the CQC in England is one model of monitoring aligned to CRPD expectations. In this model, the agency is an independent body with national reach and a mission to promote prevention through a series of monitoring actions. These monitoring actions include (a) unannounced visits, (b) meetings with patients/residents/participants, (c) published reports that provide the public access to findings, and (d) regular site visits to maintain accountability for implementation of recommendations.

Given the limited amount of information in the current body of literature, further research should include the impact of monitoring within the United States as well as the effect of specific monitoring actions on prevention of sexual violence against individuals with I/DD.



KEY FINDINGS

Based on the limited information available, the following findings for monitoring sexual violence/abuse against individuals with I/DD can be noted.

- ✓ Little is known about effective monitoring practices.

- ✓ Guidance on definitions and additional data elements for tracking sexual violence/abuse is available by the *National Center for Injury Prevention and Control of the Centers for Disease Control and Prevention* [4.1]

TRAINING

The category of training is defined as the action or process of providing individuals with I/DD or those who interact with them the knowledge and skills to prevent, detect, and report sexual violence/abuse against individuals with I/DD. A review of the literature that met inclusion criteria for this category resulted in a total of 75 relevant articles published between 1992 and 2019 with the majority of articles (61%) published between 2014 and 2018.

KEY THEMES

Key themes noted in the literature pertained almost exclusively to prevention trainings that focused on (a) providing sexual health education to individuals with I/DD and (b) sexual violence/abuse prevention for individuals with I/DD and their service providers.

SEXUAL HEALTH EDUCATION. While the expression of sexuality represents a fundamental part of being human (World Health Organization, 2013), for most individuals with I/DD such an expression remains a contentious issue (Aunos & Feldman, 2002; Kempton & Kahn, 1999; Löfgren-Mårtenson, 2004; Wings-Yanez, 2014). Despite evidence indicating their educational needs are often similar to or greater than those of individuals without disabilities, sexuality is a topic often neglected for individuals with I/DD, despite it being part of normal human development (Holland-Hall & Quint, 2017). A systematic review of the literature on the self-reported experiences, perceptions, and needs of individuals with I/DD provide ample evidence that **adults with I/DD want friendships, meaningful relationships, and intimacy** (Brown & McCann, 2018). However, many individuals with I/DD noted a tension between their self-determination and awareness of an increased risk of harm. Making informed decisions in relationships was viewed as

challenging, especially with an apparent lack of education. In the few instances where individuals with I/DD received some education, their sex education was viewed as incomplete, focusing primarily on protective measures rather than enhancing their sexual knowledge and relationships (see Yau et al., 2009). Brown and McCann summarized their review by noting that individuals with I/DD seek access to education that enables the development of their knowledge and decision-making capacity.

Unfortunately, the research literature consistently reports that individuals with I/DD have **lower levels of sexual health knowledge** compared to the general population (e.g., Stokes & Kaur, 2005; Jahoda & Pownall, 2014). As such, limited sexual knowledge and experiences, as well as other social deficits, directly collide with age appropriate sexual interest and self-expression leading to an increased risk of sexual violence/abuse (Brown-Lavoie et al., 2014). For example, Baines et al. (2008) reported an increased risk for both men and women with I/DD of having unsafe sex 50% more of the time than their peers. Yet research indicates this increased risk can be partially mediated by knowledge (Brown-Lavoie et al., 2014). However, numerous research studies underscore that most individuals with I/DD “had so little knowledge that it was difficult to see how they could negotiate sexual relationships or protect themselves from abuse” (Eastgate et al., 2011; p. 228).

A literature review on the status and effectiveness of sex education curricula based on 92 articles indicated formal, individualized, and specific sex education for individuals with I/DD is lacking (McDaniels & Fleming, 2016). More research is needed to adapt and validate curricula covering key topics such as social skills, body parts, physical and psychological changes during adolescence, reproduction, prevention of sexual abuse, sexually transmitted diseases, personal safety skills, and sexual orientation.

A recent meta-analysis by Gonzalez et al. (2018) reviewed 31 studies that examined the effectiveness of sex education programs for individuals with I/DD. A moderate effect size ($d = .64$) confirmed the program’s general effectiveness, with several notable moderators that can positively affect effectiveness: (a) single-sex groups; (b) high degree of training and experience for presenters; and (c) decision-making course components. The *Positive Choices* curriculum by the Oak Hill Center for Relationship and Sexuality Education (CRSE), for example, is specifically designed to teach skills and increase judgment about healthy relationships, sexuality, and safe boundaries for young adults with I/DD. The curriculum addresses (a) relationships and boundaries; (b) anatomy; (c) sexual intercourse; (d) sexually transmitted infection; and (e) abuse red flags. A study

by Graff et al. (2018) confirmed the positive choice curriculum was effective at increasing sexual knowledge of young adults with I/DD.

SEXUAL ABUSE PREVENTION. Based on a meta-analytic review of child sexual abuse prevention programs across 27 studies, we know that prevention programs are generally able to improve children's prevention-related knowledge and skills (Davis & Gidycz, 2000). Programs that actively engaged children in the training over multiple sessions and included modeling, rehearsal, and reinforcement produced the largest changes in performance level. The overall weighted mean effect size across all 27 studies was 1.07. A more recent meta-analysis by Del Campo and Favero (2020) confirmed the effectiveness of sexual abuse prevention programs in improving children's knowledge and skills to understand, identify, and report sexual abuse. These findings, however, were based on children without disabilities.

A literature review by Doughty and Kane (2010) on abuse-protection skills for individuals with intellectual disabilities indicated that six studies published between 1998 and 2007 focused on behavioral-skills training (e.g., instructions about appropriate and inappropriate sexual contact, instructions about appropriate responses following inappropriate sexual contact, rehearsal, corrective feedback) and applying decision-making approaches. While the reviewed studies provided trainings that were generally able to teach abuse-protection skills, they did so primarily for women with mild to moderate intellectual disabilities. Men with intellectual disabilities and individuals with severe intellectual disabilities and less effective verbal skills were notably absent.

More recently, Kim (2016) examined a sexual abuse prevention program for elementary-aged children with intellectual disabilities. The training covered (a) **body ownership**; (b) **location and names of private parts**; (c) **discrimination of appropriate and inappropriate situations** including verbal refusal strategies, physical escape, and reporting skills; (d) **review and practice** including role play with trainer; and (e) **sexual abuse lures** such as secrets, bribes, and threats. The training was completed using criterion-based role-play assessments. Results indicated that all three children with mild to moderate intellectual disabilities acquired these sexual abuse prevention skills through the program. In addition, the acquired skills were generalized and maintained for 10 weeks in real-life settings (Kim, 2016). Another training example that is specific to the target population is the ESCAPE-DD curriculum evaluated by Hickson et al. (2015). ESCAPE-DD is an abuse prevention curriculum for adults with I/DD,, which focuses on decision-making skills based on cognitive, motivational, and emotional processes. The

results showed the curriculum was effective at improving the participants' self-protective decision-making skills in six brief, hypothetical abuse scenarios.

A body of research focused on prevention training for individuals with I/DD uses **behavior skills training** (BST) to address (a) sexual health education (i.e., naming parts of the body, identifying types of relationships, providing interpersonal safety rules); (b) discrimination training (i.e., understanding appropriate and inappropriate interpersonal requests); and (c) responses to lures (i.e., strategies for responding to inappropriate requests). The latter topic was of key concern to researchers and typically involved modeling (e.g., video models, trainer models), rehearsal (e.g., role play), and feedback (e.g., praise, corrective feedback). Examples of behavioral abuse prevention training (e.g., Kim, 2016; Lumley et al., 1998) were session-based trainings over multiple weeks that included **criterion-based performance tasks** for response-to-lures protocol. These tasks typically featured role-playing scenarios and focused on teaching a four-point response to lures: *don't comply, say no, walk away, tell someone* (e.g., Bollman & Davis, 2009; Ergo-Helm et al., 2007; Miltenberger et al., 1999). It should be noted that several researchers stressed that teaching victims of sexual abuse response-to-lures protocols requires special consideration to avoid triggering past trauma. Exposure to abusive behaviors during role-play, on videos, or as part of an in-situ assessment present a risk that the learner will experience trauma. It is essential that any kind of training consider the learner's history and conduct frequent check-ins to measure distress.

To better identify who should be included in prevention training, Kim (2010) offered five key characteristics; (a) dependent on others for personal care; (b) inability to seek help or report abuse; (c) taught to be compliant; (d) social skill deficits with resulting challenges to discriminate appropriate and inappropriate personal interactions.; and (e) excluded from sex education.

Training for service providers. Given that one of the "largest group of identified perpetrators of sexual abuse is developmental disability service providers" (Bowman, Scotti, & Morris, 2010, p. 119), Bowman and colleagues examined the extent to which a sexual abuse prevention training program can affect knowledge and attitudes of service providers. The four-hour training included (a) the definition of sexual abuse, including state reporting laws relevant to children and adults; (b) sexual abuse risk factors and patterns for people with developmental disabilities; (c) HIV and AIDS information; (d) how to identify physical and behavioral signs of sexual abuse; (e) employment setting factors that contribute to sexual abuse; (f) changing negative attitudes that contribute to abuse; (g) an overview of curricular and instructional packages for teaching AIDS education,

sexuality education, and sexual abuse prevention; and (h) how to build safer environments. While the four-hour training led to a statistically significant increase in knowledge about sexual abuse issues, the post-test averages of participants only resulted in average amount of knowledge (with only 60% correct at the post-test). No changes in attitudes were observed. As such, the study demonstrated the need to train service providers through **intensive and more ongoing training opportunities**. Short, one-time workshops appeared to be insufficient.

In summary, the research literature provides numerous examples of training curricula designed for individuals with I/DD that can increase their knowledge related to sexual health and interpersonal relationships. The evidence further suggests that building capacity in this regard affords individuals with I/DD greater autonomy, self-determination, and the ability to make safer choices within relationships. Unfortunately, sexual health education for individuals with I/DD is often not addressed unless there was a problem or incident of “sexualized behavior” (Thompson et al., 2106). A more **proactive approach** to building capacity and directly teaching prevention skills is needed. Prevention of sexual violence/abuse requires additional training focused on teaching individuals with I/DD specific skills that allow them to **identify inappropriate interactions** and **use easy-to-follow scripts** to respond to lures (i.e., do not comply with request, refuse request verbally, walk away, tell a staff person).



KEY FINDINGS

Based on the available literature, the following recommendations should be considered to improve trainings that can prevent sexual violence/abuse against individuals with I/DD.

- ✓ For individuals with mild to moderate I/DD, parents and providers should consider adopting a research-based sexual health education curriculum to increase the knowledge of young adults with I/DD on topics such as basic anatomy, social skills for healthy relationships, relationship boundaries, information about intimate relationships, personal safety, and red flags for sexual violence/abuse **[5.1]**

- ✓ All individuals with I/DD should receive sexual violence/abuse prevention trainings during key developmental stages such as childhood, adolescence, and adulthood. Researchers have developed effective trainings for children, young adults, and adults with I/DD that cover basic anatomy; explain and practice discrimination of appropriate and inappropriate situations; teach refusal and reporting strategies; and practice responses to common lures [5.2]
- ✓ Service providers, especially those that work in facilities with individuals with I/DD who are dependent on others for personal care and are unable to seek help or report abuse, should receive regular training exclusively focused on sexual violence/abuse against individuals with disabilities including I/DD. While the research literature on trainings for service providers is limited, available evidence indicates the need for specialized and sustained training to increase and sustain service providers' knowledge on the topic. Required Article 9 trainings typically lack the recommended specificity (i.e., not exclusive to sexual/violence abuse), duration (i.e., only four hours or less), and frequency (i.e., recertification every three years or more) [5.3]

PREVENTION

The category of prevention is defined as the action or process of stopping sexual violence/abuse against individuals with I/DD before it occurs, for example: programs, trainings, or curricula to reduce or eliminate sexual violence/abuse against individuals with I/DD. A review of the literature that met inclusion criteria for this category resulted in a total of 24 relevant articles published between 1997 and 2019 with majority of articles (63%) published between 2014 and 2019.



KEY THEMES

Due to the large number of relevant peer-reviewed articles, an organizing framework was necessary to better understand their respective contributions. Unlike other areas (e.g. disease prevention, generalized child maltreatment prevention, generalized sexual violence prevention, intimate partner violence), no established prevention framework is currently available that has been designed specifically for the prevention of sexual violence/abuse against individuals with I/DD. Thus, examining the existing prevention frameworks from these fields was included for purposes of this review to develop an organizing framework related to preventing sexual violence/abuse against individuals with I/DD. Frameworks included in this analysis were limited to those used by the federal government and documents related to their use were sourced from government websites. Two of the selected frameworks have been informed by Nation et al.'s seminal work on prevention (2003), while the third was informed by the National Academy of Medicine's (formerly the Institute of Medicine) classifications for prevention (1997) and the Substance Abuse and Mental Health Services Administration's 2015 *Risk*

and Protective Factors. A summary and comparison of the three frameworks is featured in Table 2.

Table 2. Related Prevention Frameworks

FRAMEWORK	SECTOR	PURPOSE	LEVELS OF SERVICE	POINT IN TIME	TARGET AUDIENCE
<p>Picture of America Prevention</p> <p><i>(Centers for Disease Control and Prevention)</i></p>	Public health	Prevent disease and promote health	<p>Primary</p> <p>Secondary</p> <p>Tertiary</p>	<p>Before health effects occur</p> <p>Earliest stages of disease onset</p> <p>Post diagnosis</p>	Adopted from Wallace (2006), each layer can span the full “Spectrum of Prevention” which includes (a) influencing policy and legislation, (b) mobilizing neighborhoods and communities, (c) fostering coalitions and networks, (d) changing internal practices and policies of agencies and institutions, (e) educating healthcare providers and other professionals, (f) promoting community education, and (g) strengthening individual knowledge.
<p>Framework for Prevention of Child Maltreatment</p> <p><i>(U.S. Department of Health and Human Services)</i></p>	Child welfare	<p>Prevent maltreatment from taking place</p> <p>Reduce the negative consequences of maltreatment and prevent its occurrence</p>	<p>Primary</p> <p>Secondary</p> <p>Tertiary</p>	<p>Before maltreatment occurs</p> <p>Before maltreatment occurs</p> <p>After maltreatment has occurred or been indicated</p>	<p>General population</p> <p>Populations with a high incidence of risk factors (e.g. parental substance abuse, poverty, parental or child disability)</p> <p>Families where maltreatment has occurred</p>
<p>National Strategy for Preventing Veteran Suicide</p> <p><i>(U.S. Department of Veterans Affairs)</i></p>	Mental health & substance abuse	Prevent veteran suicide	<p>Universal</p> <p>Selective</p>	Prior to suicide but before attempt	<p>Entire veteran population within the US</p> <p>Sub-groups within the veteran population that display prominent biological, psychological or social risk factors (e.g. women veterans, Veteran’s with substance use challenges)</p>

			Indicated	Prior to suicide but may occur before and/or after an attempt	Individual Veterans with highest risk
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Key considerations of these frameworks include classification of strategies based on target population (those informed by the National Academy of Medicine’s continuum) and point in time (those informed by the ecological model of prevention). The *Framework for Prevention of Child Maltreatment* takes both into account, which represents an ideal framework for organizing strategies related to the prevention of sexual violence/abuse against individuals with I/DD. As such, we posit a **three-tiered prevention framework** that categorizes interventions according to **point in time** of administration, **target audience**, and **intensity**.

The three tiers of classification include primary, secondary, and tertiary. Initial categorization is based on target audience as articulated by the *National Academy of Medicine* (1997), wherein there is an inverse relationship between the size of the target audience and the intensity of services delivered. The second tier builds upon these strata to further refine categories by placing interventions that occur *prior* to an incident of sexual violence/abuse against an individual with I/DD in the primary and secondary categories and those taking place after an incident of sexual violence/abuse against an individual with I/DD has occurred in the tertiary category. Overlaying these categorization schemes results in a difference in purpose between primary/secondary and tertiary prevention strategies.

Depicted in **Figure 2**, the framework categorizes the strategies as follows:

- **Primary Prevention Strategies (PPS):** Strategies designed to prevent sexual violence/abuse against individuals with I/DD from ever being committed. These target the **whole population** of individuals with I/DD and their caregivers. These strategies are deployed prior to any incidence of sexual violence occurring.
- **Secondary Prevention Strategies (SPS):** Strategies designed to prevent sexual violence/abuse against individuals with I/DD from being committed but only deployed to **individuals and subgroups** within the broader population of individuals with I/DD who display increased risk for victimization and their caregivers. Like PPS, SPS are also applied prior to an incident taking place.

- **Tertiary Prevention Strategies (TPS):** Strategies designed to (a) prevent re-victimization of individuals with I/DD who have already experienced sexual violence/abuse and (b) mitigate the short- and long-term effects of the incident. TPS address the whole population of individuals with I/DD who have experienced sexual violence/abuse and their caretakers.

. In this framework, it is important to note the intended recipients of prevention strategies are substantially different from existing models. Strategies designed to prevent sexual violence/abuse against individuals with I/DD must target both the **individual and their caregivers**. In this context, caregivers can be understood as any individual, group, organization, or institution tasked with providing care or assistance to an individual with I/DD. It should be noted that at present, most of the prevention strategies documented in the body of peer-reviewed literature target either the individual with I/DD or their caregiver but not both. We have addressed these works but also recommend prevention strategies be bolstered to address both groups.

PRIMARY PREVENTION

Primary prevention strategies (PPS) are those designed to prevent sexual violence/abuse against individuals with I/DD from ever being committed. These target the whole population of individuals with I/DD **and their caregivers**. These strategies are deployed prior to any incidence of sexual violence occurring.

STANDARD FOR QUALITY. Primary prevention strategies can take different forms including policy and governance structure, sexual abuse education for individuals with I/DD and their caregivers, and whole population training and education programs for individuals with I/DD.

The quality of the primary prevention approach is dependent on which strategy is employed. Understanding quality for primary prevention programs is of utmost importance as the simple existence of a primary prevention strategy does not guarantee its efficacy. Effectiveness of policy and governance structure can be judged on society's faith and trust in the structure, and presence of key ingredients such as a financially and

administratively separate oversight mechanism, unannounced inspections, and private meetings with patients to hear their experiences (Laing, 2017). Alternatively, population-based education programs can be evaluated and the standard of quality can be empirically assessed. An effective education or behavior based strategy will have evidence of effectiveness using empirical measures such as pre-post test level of knowledge or increased level of knowledge as compared to a control group. Curtiss et al. (2019) further recommended that sex education programs be comprehensive, theoretically based, focused on skill development with sufficient follow-up, and include participant ownership. In the sections that follow, sexual health education; policy; oversight; abuse awareness; and education are discussed as the three categories of primary prevention.

SEXUAL HEALTH EDUCATION. A common theme was the importance of high quality, age and developmentally appropriate sexual health education for all people that have I/DD and/or for their caregivers and professional support providers. Many articles emphasized the importance of sex education and stated that a complete lack of body awareness or sexual education puts individuals at a higher risk of being sexually abused because the individual is unaware of appropriate boundaries, their right to say no, and the markers of healthy relationships (Barnard-Brak et al., 2014; Frawley & Wilson, 2016; Graff et al., 2018; Martinello, 2014).

The literature addressed the common myths and perceptions around sexuality and individuals with I/DD. Historically, individuals with I/DD have been viewed as asexual or sexual deviants and this has led to reluctance to provide sexual education (Dupras, 2014; Frawley & Wilson, 2016). Some articles mentioned that either sexual education was not provided because individuals with I/DD were seen as not being interested in or capable of sexual relationships or a misplaced fear that exposure to sexuality via educational programs would lead to increased interest and participation in sexual activity (Curtiss et al., 2019). Research acknowledged that caregivers and professionals have an increased presence and role in helping an individual with I/DD navigate life and often hold conservative and risk-averse views on sexuality and relationships, which lead to restrictive and rules-based teaching that limits a young person's access to information (Frawley & Wilson, 2016). Consequently, young adults with I/DD expressed the desire for more information and to talk with people other than parents or staff about sexuality (Frawley & Wilson, 2016).

Components of sexual health education programs in the literature differed greatly in terms of content and depth of coverage. Typical content for these types of prevention trainings included (see Wolfe et al., 2019):

- Human development and sexual health including information about puberty process, reproductive and sexual anatomy, reproduction, contraception, and STDs.
- Protection from abuse should include information such as identifying behaviors that constitute abuse, how to avoid situations where abuse may occur, saying no to attempted unwanted sexual advances, and reporting the situation to a person in authority.
- Although not present in all education programs, some authors recommend including information on maintaining healthy relationships and negotiating sexual boundaries with partners.

The studies reviewed suggested that the most effective ways of teaching sexual health content was through the use of multiple teaching methods such as modeling, role-play, rehearsal, and practicing skills taught in class (Graff et al., 2018). Sexual health education programs should contain the appropriate content, be comprehensive, and sensitive to the target audience (McDaniels & Fleming, 2016). Additionally, programs should provide individuals with content knowledge and effectively teach individuals to apply that knowledge (McDaniels & Fleming 2016). Multiple studies also emphasize the importance of adapting any sexual education curriculum to target audience needs (Frawley & Wilson, 2016). For instance, this could include topics related to body parts, physical and psychological changes, sexuality as a social skill, reproduction, prevention of sexual abuse, STD education, personal safety skills, and sexual orientation (McDaniels & Fleming, 2016).

POLICY, GOVERNANCE, AND OVERSIGHT. Most of the literature on this topic was focused on experiences in the United Kingdom as a result of scandals and abuse of patients with disabilities in residential group homes (Laing, 2017). Laing (2017) argued effective and independent oversight can play a crucial role in ensuring quality of care, safety, and violence prevention for individuals with disabilities. Some **components of effective oversight** identified included (a) administrative and financial autonomy, (b) unannounced inspections of group homes, (c) the importance of meeting privately with

patients to hear potential complaints, and (d) the necessity of reporting findings and following up on recommendations.

While Laing's 2017 work focused on residential group homes for individuals with disabilities, the author argued that these oversight mechanisms can be extended to service providers in the community as well. This approach would call for monitors whose role is conducting oversight that achieves a balance between protecting individuals while not interfering with autonomy. Although this would require significantly more funding, it could reach a far greater number of individuals with I/DD.

ABUSE AWARENESS AND EDUCATION. Abuse awareness and education programs can be categorized as primary or secondary prevention strategies depending upon the intensity and customization of material for higher risk populations. These programs are more common than sexual education and policy, governance, and oversight approaches. Additionally, more empirical studies have been conducted on these strategies. The majority of these studies have been guided by theory and common core components that provide a framework for understanding quality within abuse awareness and education programs.

Most abuse awareness programs are either behavior-based or cognitive-based. Behavior-based education and training focuses on teaching individuals with disabilities to recognize signs of abuse, say “no” to an abuser, leave a situation where abuse is possible, and report their confrontation to someone in authority (Wilczynski et al., 2015). Cognitive-based education programs include training typically found in the behavioral-based education listed above but also include training for people in decision-making (Wilczynski et al., 2015).

One example of a particularly prominent and fairly well-studied cognitive-based abuse awareness education program is called ESCAPE and the adapted ESCAPE-DD. The program is designed to help the individual distinguish between healthy and unhealthy relationships, establish empowering self-beliefs and prioritize safety of oneself, and identify and process emotions associated with abuse (Hickson et al., 2015). The program also aims to help the individual acquire and apply effective decision-making strategies by identifying a situation as abusive, generating alternatives, considering consequences of alternatives, and choosing a course of action in an abuse situation (Hickson et al., 2015). Although the program focuses heavily on decision-making, it also includes an in-depth discussion of feelings and motivations which some authors cite as a potential reason for its effectiveness (Doughty & Kane, 2010). In an analysis of the ESCAPE-DD program, which

was adapted to be suitable for men as well as women, there were significant gains in overall effective decision-making and in immediate situational decision making between pre-test and post-test for intervention groups. However, there was no significant difference between intervention and control groups with regards to problem awareness or identification of a situation as potentially dangerous (Hickson et al., 2015). One author praised the efficacy of the ESCAPE trainings and suggested that one potential way to further strengthen the program would be to add a behavioral component that included role-playing and situational tests of decision-making skills (Doughty & Kane, 2010).

Researchers in the field have also developed internet-based abuse and safety awareness programs for both men and women in an effort to create a safe, accessible, and relevant form of abuse awareness training (Lund et al., 2015). The programs are the Women's Safer and Stronger Program and the adaptation for men, the Men's Safer and Stronger Program. These programs are audio and computer assisted self-interviews coupled with video vignettes of men and women who are survivors of abuse. Although the original program was developed as a research tool to gather data on prevalence of abuse, both programs also provided information on violence awareness (Oschwald et al., 2009). Participants in a pilot study reported the program provided them with helpful and relevant information about safety (Lund et al., 2015).

An additional consideration posed by literature is that most evaluations of knowledge retention from abuse education programs show a significant decline in skills after three months for even the best programs (Doughty & Kane, 2010). Due to these knowledge maintenance challenges, Doughty and Kane (2010) recommended "booster sessions" to promote knowledge maintenance.

Some common themes taught in both effective cognitive- and behavior-based programs include teaching abuse knowledge early in the training, training individuals on the skills of being able to identify a dangerous situation, leaving the situation without complying with an abuser, and reporting the situation. One strength of the cognitive trainings was the discussion of emotions, thoughts, and feelings. One strength of the behavior-based training was the practicing and assessment of skills in situational role-play (Doughty & Kane, 2010).

SECONDARY PREVENTION

Secondary prevention strategies (SPS) are strategies designed to prevent sexual violence/abuse against individuals with I/DD deployed specifically to individuals and

subgroups within the broader population of individuals with I/DD who display an increased risk for victimization and their caregivers. Like PPS, SPS are also applied prior to an incident taking place. Examples of targeted subgroups within the broader population could include children with I/DD, individuals needing personal care or hygiene services, individuals with severe communication barriers, and individuals with multiple disabilities. As noted earlier, these groups can be at even higher risk of sexual assault than the larger population of people with I/DD (Barger et al., 2009; Nelsen & Bryen, 2003; Byren et al., 2003; Martinello, 2014).

STANDARD FOR QUALITY. Reviews of the literature indicate that there are relatively few secondary prevention programs that are designed to target specific high-risk subgroups within the larger population of people with I/DD. For those that do exist, the primary standard of quality used to determine effectiveness is empirically grounded evaluation and assessment. Pre-post test methods or comparison to control groups are most commonly used to assess achievement of desired outcomes. Within the body of literature, sexual health education programs most commonly met the standard for quality.

SEXUAL HEALTH EDUCATION. The majority of targeted prevention programs identified in literature are geared towards children. Children with I/DD are thought to have higher risks of being sexually abused because of the characteristics that make them vulnerable, such as dependency, need to belong, and lack of knowledge about sexuality (Wissink et al., 2015). Research supports this claim by showing increased prevalence of sexual violence against children with I/DD even as compared to children with other types of disabilities (Jones et al., 2012).

Special emphasis is given in the literature to the importance of children learning anatomical names of body parts and appropriate boundaries. One article mentioned the unique vulnerability of children with I/DD that need personal care assistance. Martinello explained (2014) additional risk factors for children needing personal care services are related to the fact that personal care services often take place in areas that provide privacy, which provide ample opportunity for a mal-intentioned person to commit an act of sexual violence/abuse. Additionally, children are encouraged to comply with tasks and may not be able to distinguish between passive receipt of necessary personal care such as bathing and abuse. As a remedy, the author encourages sexuality education.

One program in particular was developed specifically for children with I/DD in accordance with their intellectual and developmental characteristics. The strategy used

story books with illustration that were developed with input from child psychiatrists and psychologists to ensure appropriateness and suitability for children. The books were read to the children once a week over the course of four weeks. Then, parents were instructed to read the stories to the children at home three times per week. The topics covered included learning the correct names for body parts, learning about appropriate touch, interpreting and responding to inappropriate confrontations by strangers or their relatives, and reporting confrontations to their parent (Kucuk et al., 2017). Evaluation of the study showed that knowledge in each of these topical areas significantly increased after the program when compared to knowledge prior to the program (Kucuk et al., 2017).

TERTIARY PREVENTION

Tertiary prevention strategies (TPS) are strategies designed to (a) prevent re-victimization of individuals with I/DD who have already been the victim of sexual violence and (b) mitigate the short- and long-term effects of the incident. TPS address the whole population of individuals with I/DD who have experienced sexual violence/abuse and their caretakers. Though not well documented, where research has specifically sought to quantify re-victimization rates in individuals with I/DD, estimates state that children with I/DD are up to 42% more likely to experience recurring episodes of maltreatment than their non-disabled peers (Fisher et al., 2008).

Very little research has been conducted to identify effective tertiary prevention services for individuals with I/DD that have suffered sexual abuse (Dupras, 2014; Wilczynski, 2015). One tertiary prevention/treatment strategy (Trauma-Focused Cognitive Behavioral Therapy) is well supported and has been effectively adapted for individuals with disabilities. Mikton et al. conducted a systematic analysis of preventions and interventions related to sexual abuse/violence against individuals with I/DD. Their work identified two tertiary prevention programs for adults: a program aimed at providing support and preparation for court and the other a peer support group for female victims of violence/abuse.

STANDARD FOR QUALITY. Standards for quality of tertiary prevention strategies are less well documented than those of primary and secondary, however Saunders et al. (2003) provided some insight to what is necessary for a TPS to be impactful. Specifically, the strategy must be theoretically informed and able to produce

empirical data of its efficacy. Further, there should be no evidence of risk of harm to those receiving the treatment

Utilizing the quality criteria articulated above, review of current literature surfaced as particularly well-supported. Trauma-focused cognitive behavioral therapy (TF-CBT) has been shown to be effective for children with disabilities when clinicians modify the intervention. As a baseline intervention, TF-CBT includes components of psychoeducation about abuse and typical reactions, gradual exposure techniques, stress reduction techniques, cognitive reframing, parental participation and instructions for parents on managing child behavior (Saunders et al., 2003). Modifications for efficacy with children with disabilities include shorter session times to accommodate shorter attention spans, using visual supports, and breaking components into smaller steps (Wilcynski et al., 2015).



KEY FINDINGS

Based on the available literature, the following recommendations should be considered to prevent sexual violence/abuse against individuals with I/DD.

- ✓ Provide high quality, age and developmentally appropriate sexuality education for all people that have I/DD and/or for their caregivers and professional support providers **[6.1]**
- ✓ Sexual health education programs should employ the use of multiple teaching methods such as modeling, role-play, rehearsal, and practicing skills taught in class **[6.2]**
- ✓ Content of sexual education classes should include topics related to body parts, physical and psychological changes, sexuality as a social skill, reproduction, prevention of sexual abuse, STD education, personal safety skills, and sexual orientation **[6.3]**
- ✓ Effective and independent oversight should be established to monitor services provided to individuals with I/DD. To be considered effective and independent, oversight should have administrative and financial autonomy, oversight personnel should conduct unannounced inspections of group homes, oversight personnel should meet privately with patients to hear

potential complaints, and oversight bodies should report findings and follow up on recommendations **[6.4]**

- ✓ Empirically supported abuse education and awareness programs should be provided and should contain the following elements: (a) teach abuse knowledge early in the training; (b) train individuals on the skills of being able to identify a dangerous situation; (c) train the individual on how to leave the situation without complying with abuse; (d) how to report the situation to a trusted person in a position of authority; (e) if possible, the strengths of both cognitive trainings and behavior based training should be combined so programs include discussion of emotions, thoughts, and feelings as well as the practicing and assessment of skills in situational role-play; and (f) provide “booster sessions” to individuals following initial program to increase knowledge retention **[6.5]**
- ✓ Trauma-Focused Cognitive Behavioral Therapy should be provided to individuals following experience with sexual abuse **[6.6]**

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JANUARY 2021

DAY TREATMENT & RESIDENTIAL PROVIDERS FOR
INDIVIDUALS WITH INTELLECTUAL AND
DEVELOPMENTAL DISABILITIES

STATE OF THE PROVIDERS

Alexander Kurz, PhD
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Annual Provider Survey

DAY TREATMENT & RESIDENTIAL PROVIDERS FOR INDIVIDUALS WITH I/DD

STATE OF THE PROVIDERS

Nearly 13% of Arizonans reported having some type of disability, which represents over 880,000 individuals (American Community Survey, 2018). Almost half of those individuals reported having either a cognitive or ambulatory disability. Many of these individuals with I/DD receive services from day treatment providers or live in residential group home facilities. There were 207 day treatment and 147 residential group home providers operating in the state of Arizona during 2020, according to data provided by the Department of Economic Security's Division for Developmental Disabilities (DDD). Figures A and B show the respective geographic location of all contacted day treatment and residential group home providers.

To determine the current level of implementation of research-based practices and recommendations based on the recently published *State of the Research* literature review (Kurz, Velasquez, Mullins, & Nicely, 2020), the present section provides survey data based on voluntary responses received from a sample of day treatment ($N=69$) and residential group home ($N=55$) providers. We begin by reviewing the measured survey constructs, administration procedures, and survey reliabilities followed by a detailed summary of initial findings.

Figure A. Geographic locations of day treatment programs

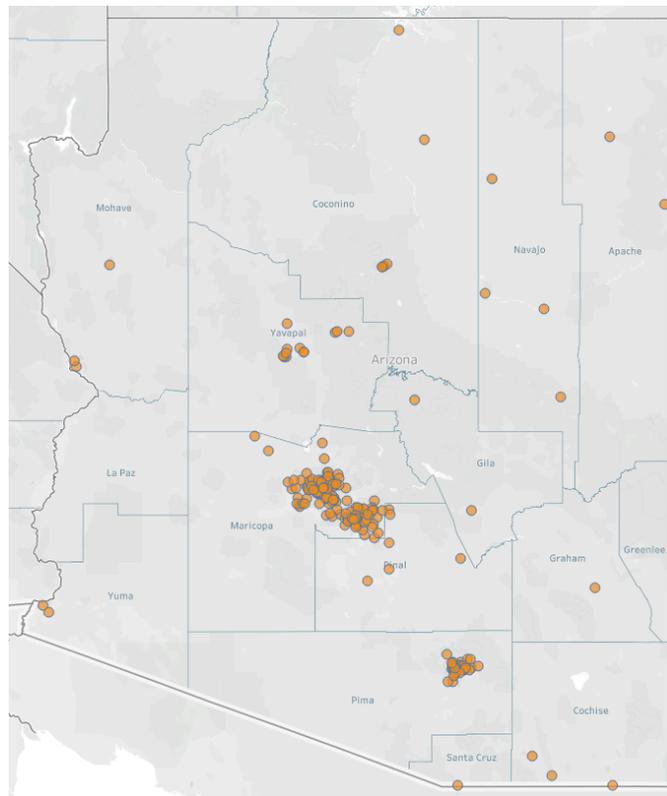
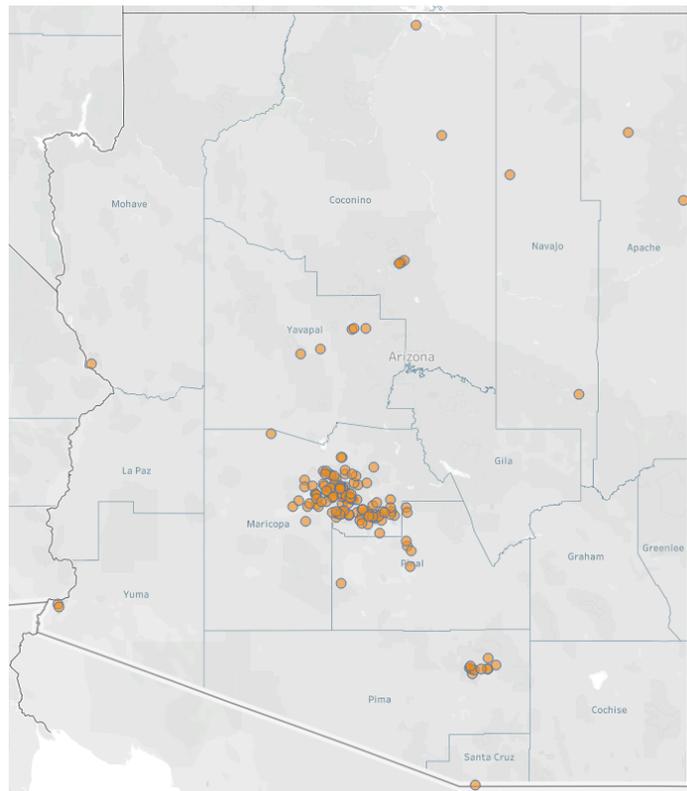


Figure B. Geographic locations of residential group homes



SURVEY CONSTRUCTS

Both surveys were designed to (a) gather **contextual information** on day treatment and residential group home providers operating in the state of Arizona and (b) determine their self-reported **level of implementation** of research-based recommendations identified in the academic research literature to improve the detection, reporting, tracking, monitoring, training, and prevention of sexual violence/abuse against children and adults with I/DD. Both surveys featured the following topics using multiple five-point Likert scale items and open-ended questions (46 questions total):

- **General information** (11 questions)
 - 10 items
 - 1 open-ended
- **Detection** (12 questions)
 - 8 items
 - 4 open-ended
- **Reporting** (10 questions)
 - 6 items
 - 4 open-ended
- **Tracking** (2 questions)
 - 2 items
- **Monitoring** (5 questions)
 - 4 items
 - 1 open-ended
- **Prevention** (8 questions)
 - 7 items
 - 1 open-ended

The items under the general information section featured multiple choice questions to provide descriptive information on the respective providers. The Likert scale items under the remaining topics allowed respondents to rate the extent to which a given statement applied to their facility ranging from *strongly agree* to *strongly disagree*. Open-ended questions allowed respondents to provide additional descriptive information such as examples related to certain statements (e.g., types of documents, types of trainings). The use of Likert scale items was purposeful to allow for repeated annual survey

administrations and track changes over time in response to newly implemented policies and practices.

SURVEY PROCEDURES

Both surveys were administered online in the Fall of 2020 during a two-week response period. All providers were contacted via email on the basis of a list made available directly to the research team by the DDD. To ensure receipt by administrators, each facility was contacted by a research assistant with a follow-up phone call. The research assistant explained the survey purpose, its main topics, and answered any questions. Both online surveys began with a statement that explained purpose, topics, and confidentiality. Participants were allowed to exit the survey at any time.

For the **day treatment providers**, completion statistics indicated an estimated completion rate of 71%, with an average completion time of 12 minutes. A total of 69 individuals provided responses (omitting some open response items), with 53 individuals completing the full survey. For the **group home providers**, completion statistics indicated an estimated completion rate of 70% with an average completion time of 12 minutes. A total of 55 individuals provided responses (omitting some open response items), with 33 individuals completing the full survey.

SURVEY RELIABILITY

At a minimum, each survey administration should provide data on its reliability via a measure of internal consistency, typically reported via **Cronbach's alpha** (α). Alpha can range between 0 and 1.0 indicating the degree to which the various survey items are related. In a well constructed survey, one would expect ratings on items assessing the same construct to be related. In general, the following interpretations are accepted:

- $\alpha > 0.9$ – Excellent
- $0.7 \leq \alpha < 0.9$ – Good
- $0.6 \leq \alpha < 0.7$ – Acceptable
- $0.5 \leq \alpha < 0.6$ – Poor
- $\alpha < 0.5$ - Unacceptable

The overall reliability for the **day treatment survey** was **0.96**. The reliabilities for the six main constructs fell within the **good to excellent range**: 0.93 for detection, 0.87 for reporting, 0.99 for tracking, 0.81 for monitoring, and 0.90 for prevention. For tracking,

the alpha was too high to warrant two separate items. For future iterations of the survey, we recommend replacing one item with a new one. The overall reliability for the residential **group home survey** was **0.94**. Similar to the day treatment survey, the reliabilities for the six main constructs fell within the **good to excellent range**: 0.94 for detection, 0.81 for reporting, 0.98 for tracking, 0.88 for monitoring, and 0.86 for prevention. Again, the alpha for tracking was extremely high providing further evidence that the present two items are too similar.

In summary, the observed reliabilities for the present samples of day treatment and group home respondents were very good and appropriate for their intended purpose. As noted, future revisions should consider removing one item related to tracking and/or replacing one item with a new one.

RESULTS FOR DAY TREATMENT PROVIDERS

The sample was comprised primarily of **administrators** (77%) as well as owners (23%) who provided day treatment services in mostly **urban settings** (60%) as well as rural settings (37%). The majority of those providers (58%) operated only **one program**. The average number of programs was 2.4 with a range of 1 to 21 programs. Based on the general information provided by respondents, the majority of programs featured **multiple, mostly female staff members** with little turnover (see Figures 1-3). The majority of providers served **more than 16 individuals** with I/DD split between male and female participants. All day treatment providers served **adults with I/DD** with several also serving children (ages 6 to 18) and elderly adults (65 or older) with I/DD. While the majority of disability limitations noted were cognitive (96%), each provider served a wide a range of disabilities (see Figures 4-7).

Figure 1. Average staff size per program

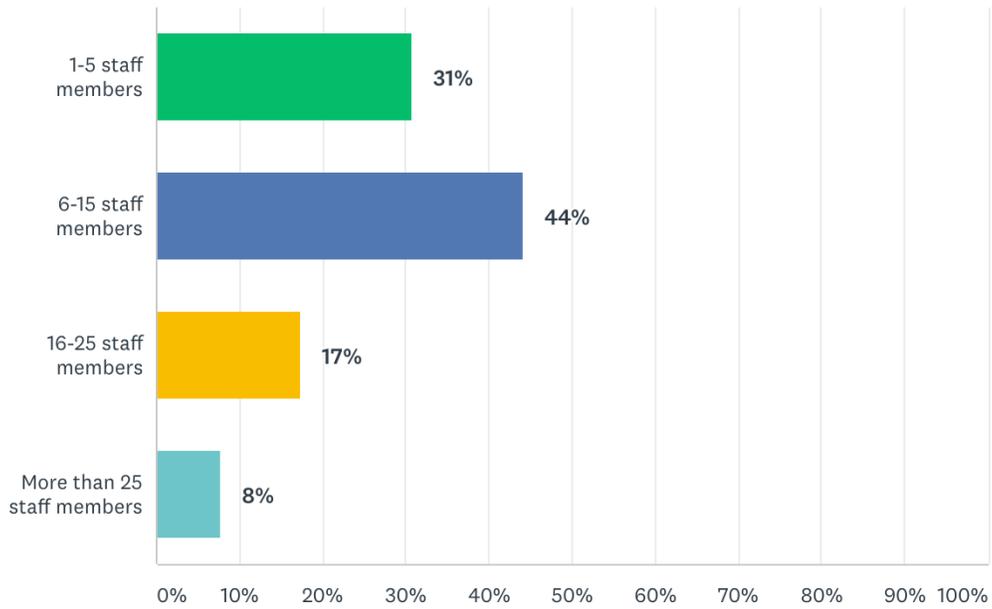


Figure 2. Gender ratio of staff

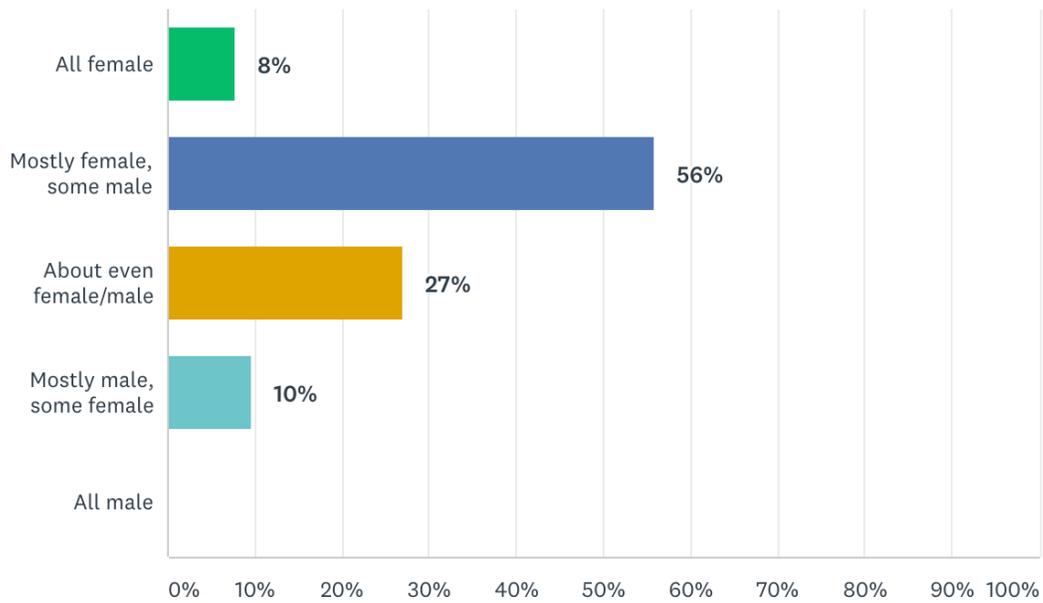


Figure 3. Estimated staff turnover

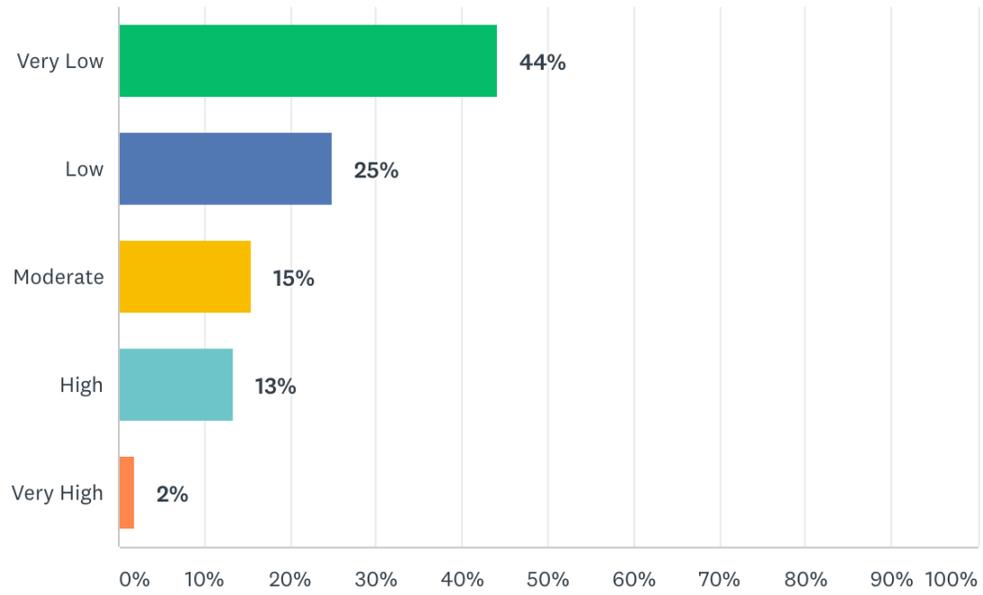


Figure 4. Average number of participants with I/DD per program

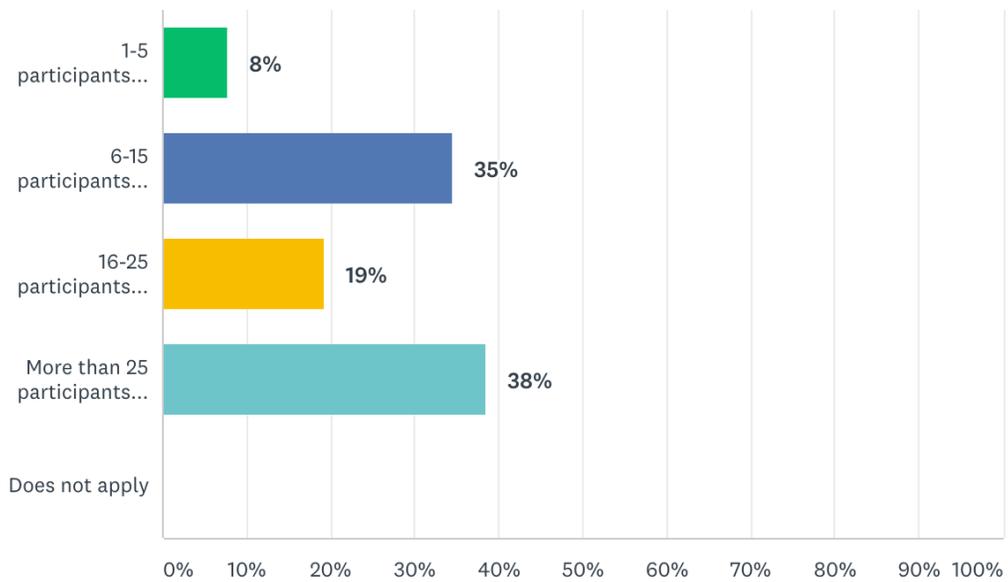


Figure 5. Gender of participants with I/DD

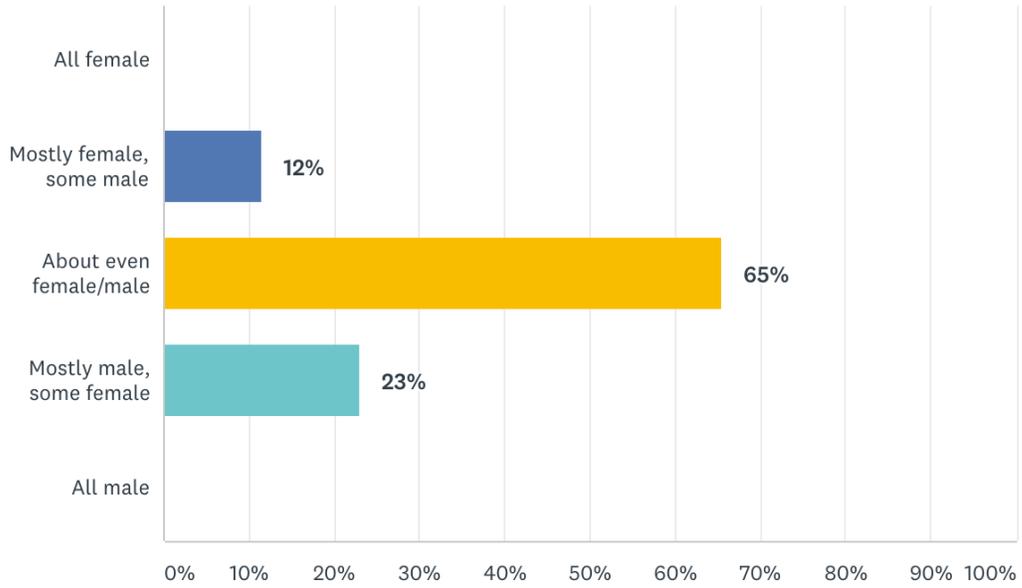


Figure 6. Age groups of participants with I/DD served

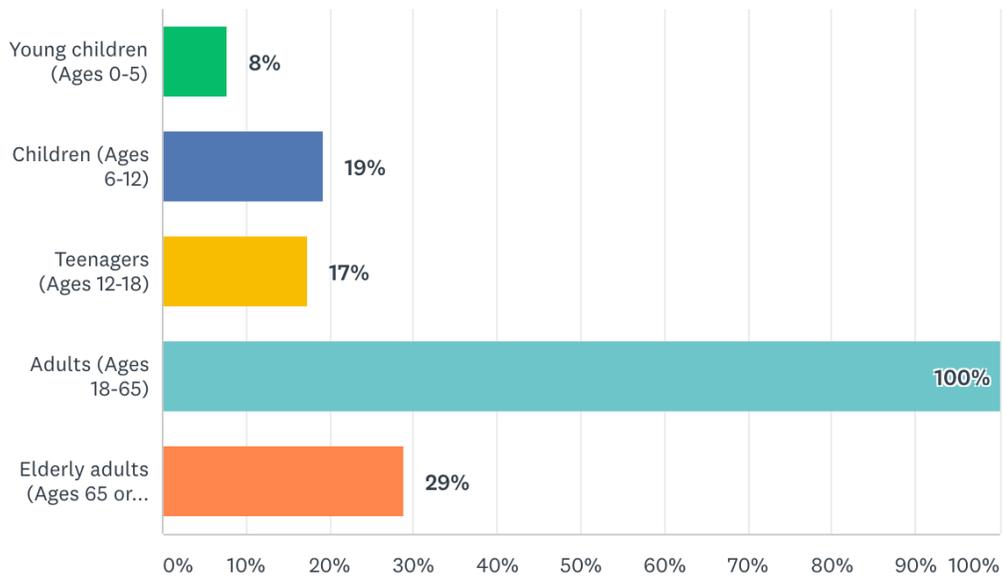
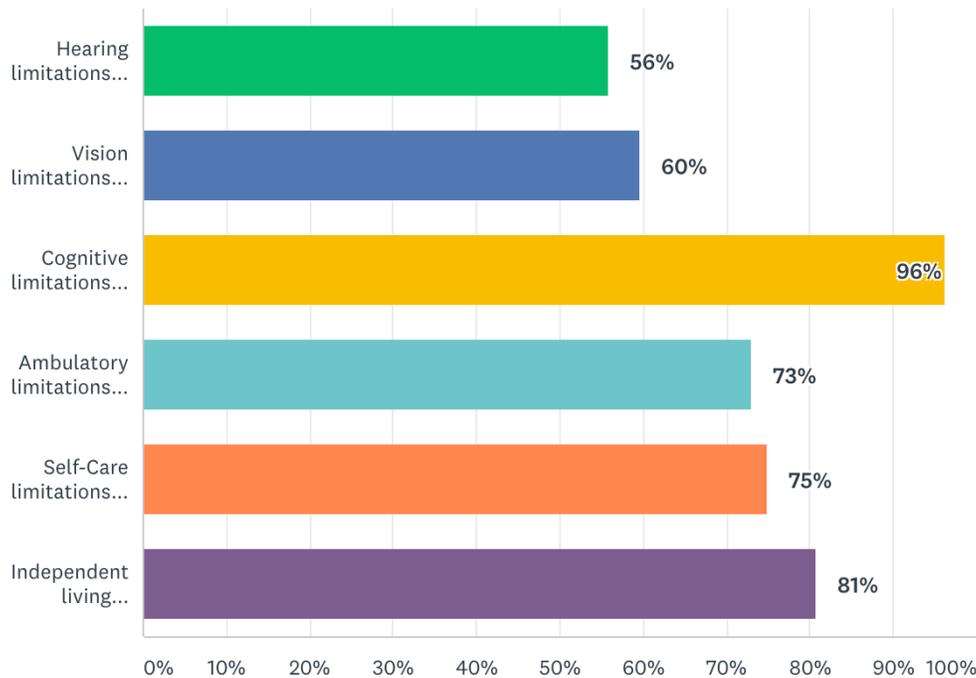


Figure 7. Disabilities served based on limitations



DETECTION. One of the key recommendations based on the research literature was the need to have policy and procedures in place that can **assess the risk** of sexual violence/abuse against individuals with I/DD [see 1.1-1.4]. Specific examples included **risk assessments** and universal **screening assessments**, including audio computer-assisted self-interviews (ACASIs). The majority (73%) of day treatment providers agreed or strongly agreed that they had policies and procedures in place for determining the risk using such tools as risk assessments at intake or periodic screening (see Figure 8). On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 2.1 with a standard deviation of 1.1. When asked to provide specific tools, the most frequent examples included written policies provided at orientation, staff trainings (e.g., Article 9), and risk assessments at intake. Some notable mentions included individualized service plans with details on risk and/or prevention of sexual violence/abuse strategies specific to the participant, same-sex assignments (i.e., female-only staff for female participants), and camera monitoring of provider sessions.

Figure 8. Percentage of day treatment providers with policies/procedures in place for determining the risk of sexual violence/abuse against participants with I/DD

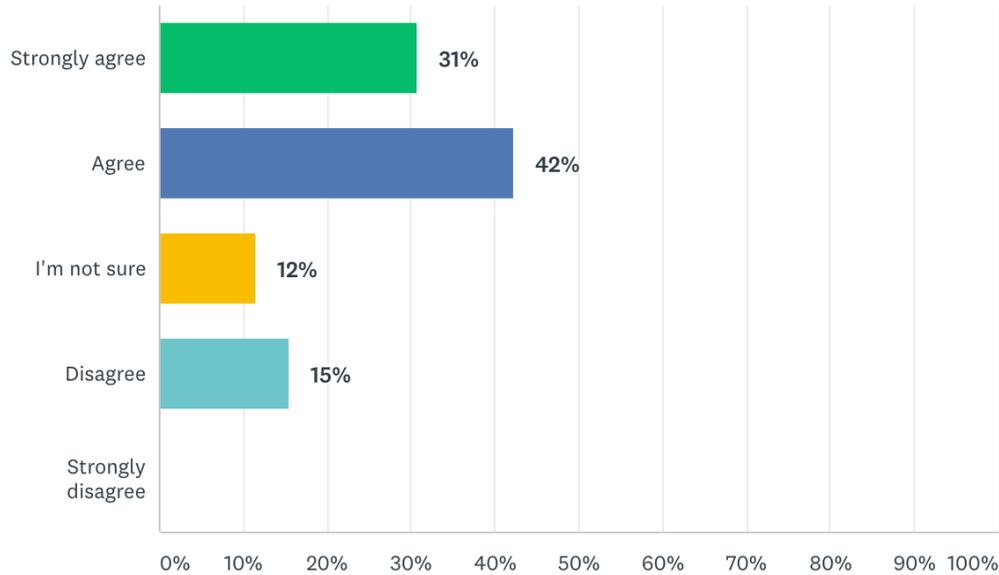


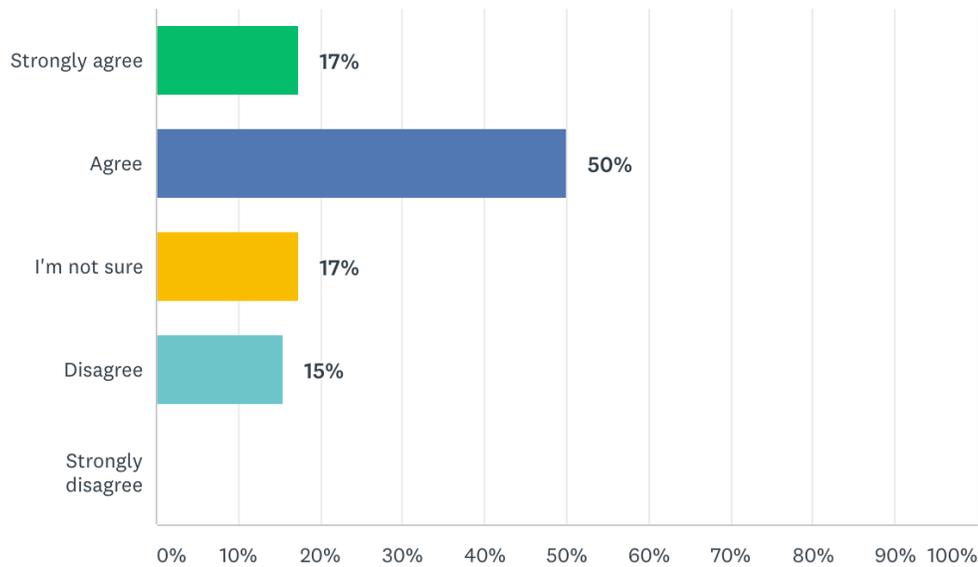
Figure 9. Word cloud based on key word frequencies



When asked about the presence of an **internal process for detecting** the presence of sexual violence/abuse against participants with I/DD (e.g., tip sheet with warning signs), the majority (67%) of day treatment providers agreed or strongly agreed that processes were in place. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 2.3 with a standard deviation of 1.0. When asked about specific examples, the answers were more generic, pointing to previously mentioned staff trainings. Some notable mentions included daily body

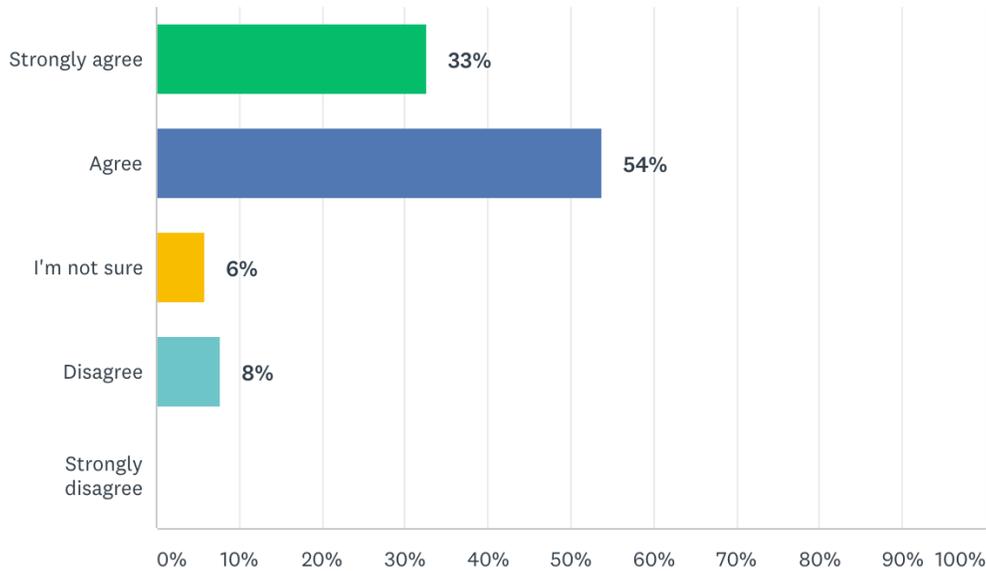
checks upon arrival and a partner system (i.e., two providers per participant) to review a checklist of signs.

Figure 10. Percentage of day treatment providers with internal process for detecting the presence of sexual violence/abuse against individuals with I/DD



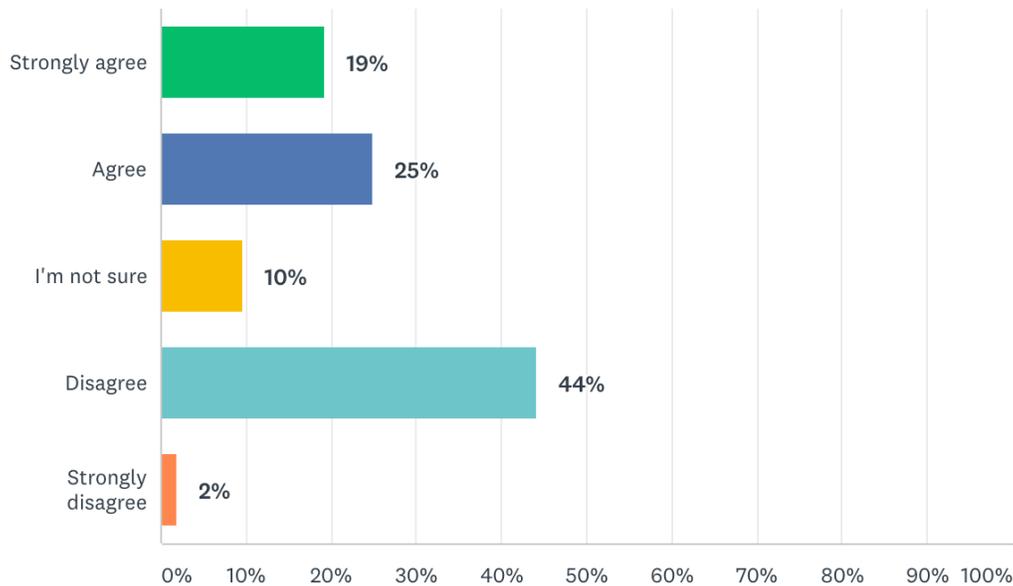
When asked about staff knowledge related to **risk factors** for sexual violence/abuse against participants with I/DD, the vast majority (87%) of day treatment providers agreed or strongly agreed that their staff was familiar with risk factors. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 1.9 with a standard deviation of 0.9.

Figure 11. Percentage of day treatment providers with staff knowledge about risk factors for sexual violence/abuse against individuals with I/DD



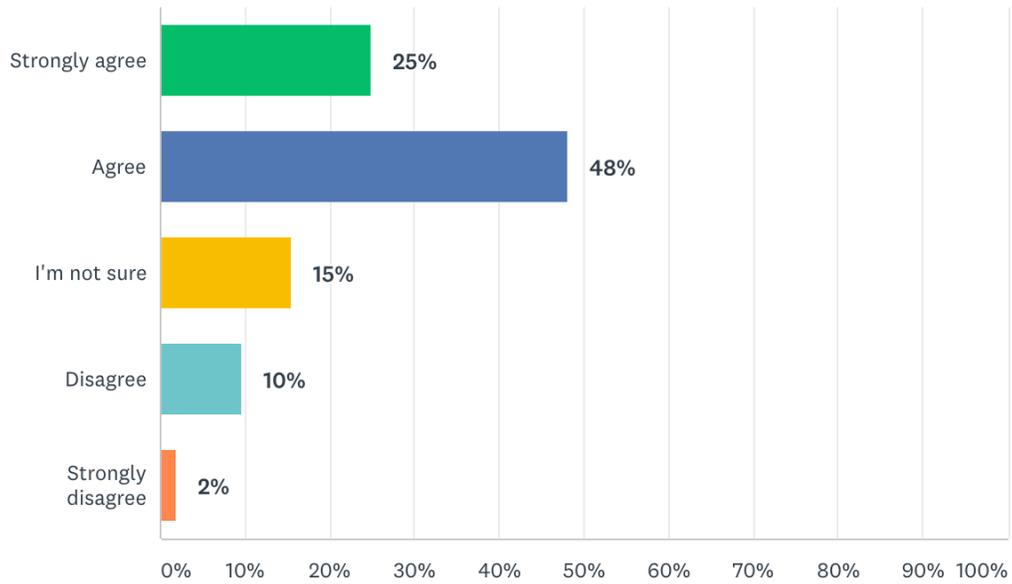
When asked about use of **screening or measurement tools to determine risk** for sexual violence/abuse against participants with I/DD, less than half (44%) of day treatment providers agreed or strongly agreed that their organization used some type of measurement tool to determine risk. This finding appears to be at odds with earlier questions (see Figures 7 and 8) for which respondents indicated having risk assessments available. A possible explanation for this discrepancy is the focus on a “measurement tool” for purposes of assessing risk. As such, it appears that the term “risk assessment” noted earlier may have referred to an informal process (e.g., simple check list) rather than formal measurement tool (e.g., rating scale with psychometric properties including cut scores for risk levels). On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 2.8 with a standard deviation of 1.3.

Figure 12. Percentage of day treatment providers that use screening or measurement tools to determine risk of sexual violence/abuse against individuals with I/DD



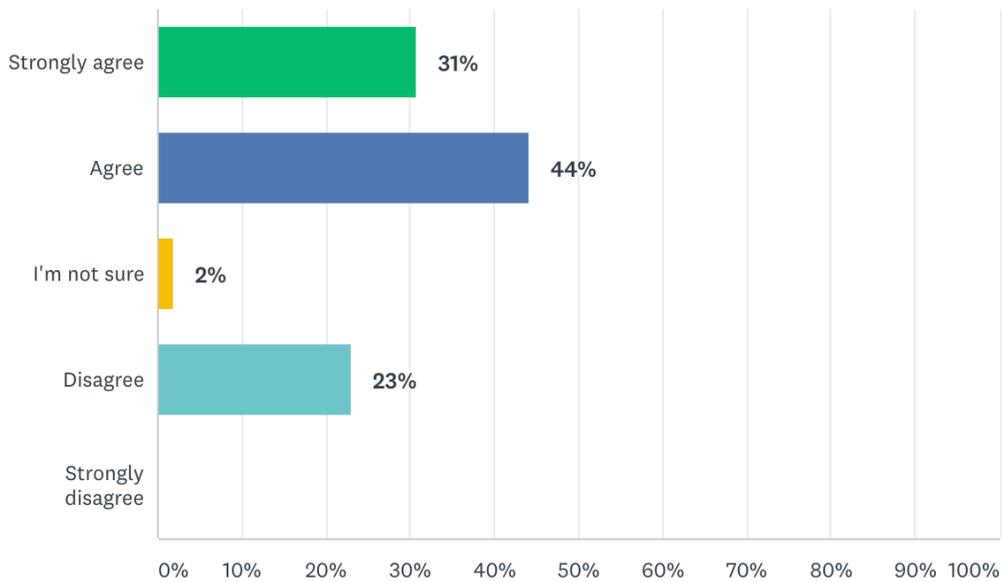
When asked about staff understanding of the risks involved when **asking individuals with I/DD about possible sexual violence/abuse**, the majority (73%) of day treatment providers agreed or strongly agreed that their staff was aware. As noted in the research literature, only trained professionals should question individuals with I/DD without any real or perceived threats of retaliation present [see 1.5]. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 2.2 with a standard deviation of 1.0.

Figure 13. Percentage of day treatment providers with staff that understands the risks involved with asking individuals with I/DD about possible sexual violence/abuse.



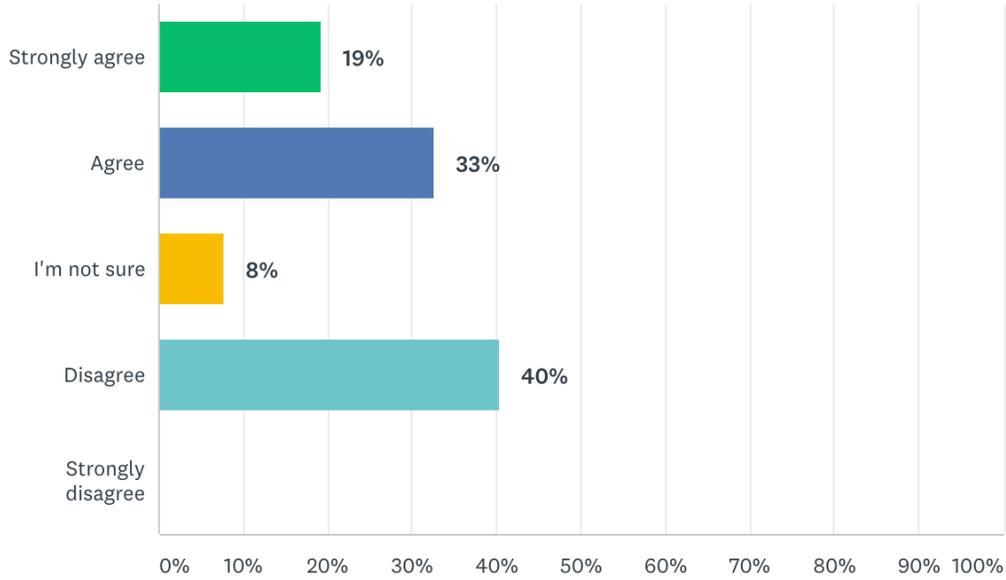
When asked about **staff trainings on risk factors** for sexual violence/abuse against participants with I/DD, the majority (75%) of day treatment providers agreed or strongly agreed their staff were trained. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 2.2 with a standard deviation of 1.1.

Figure 14. Percentage of day treatment providers with staff trainings on risk factors for sexual violence/abuse against participants with I/DD



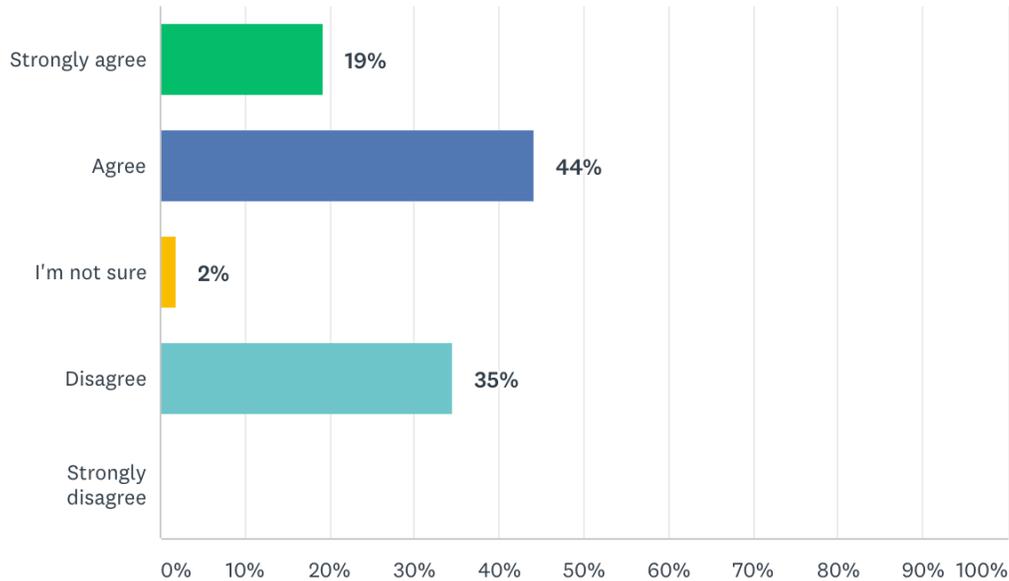
When asked about **staff trainings on screening or measurement tools** to determine the risk or presence of sexual violence/abuse against participants with I/DD, about half (52%) of day treatment providers agreed or strongly agreed that their staff were trained. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 2.7 with a standard deviation of 1.2.

Figure 15. Percentage of day treatment providers with staff trainings on screening or measurement tools to determine the risk or presence of sexual violence/abuse against participants with I/DD



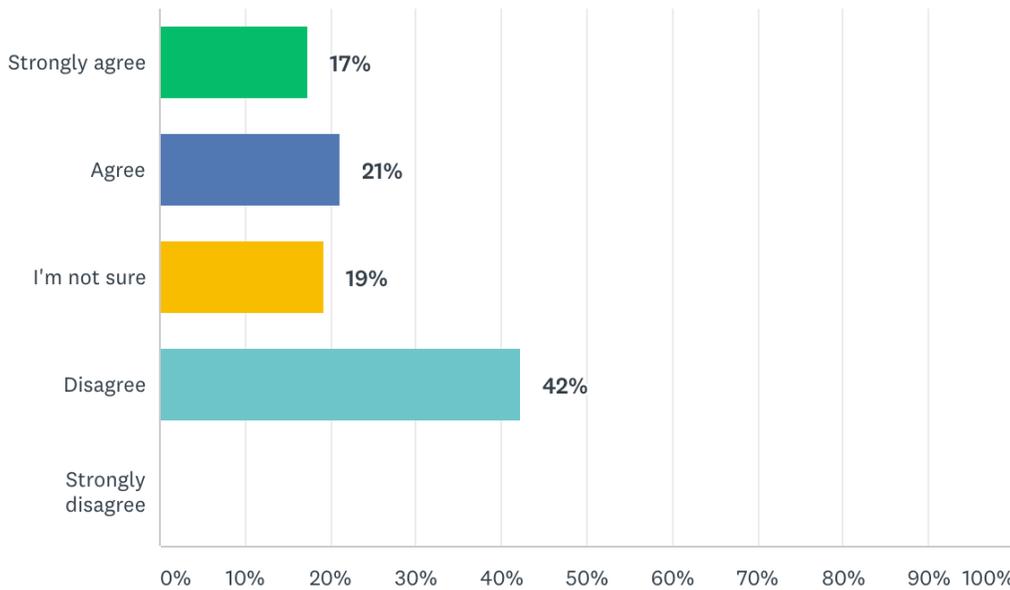
When asked about **staff trainings on the risks involved with asking individuals with I/DD about possible sexual violence/abuse**, the majority (63%) of day treatment providers agreed or strongly agreed that their staff were trained. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 2.5 with a standard deviation of 1.2.

Figure 16. Percentage of day treatment providers with staff trainings on the risks involved with asking individuals with I/DD about possible sexual violence/abuse



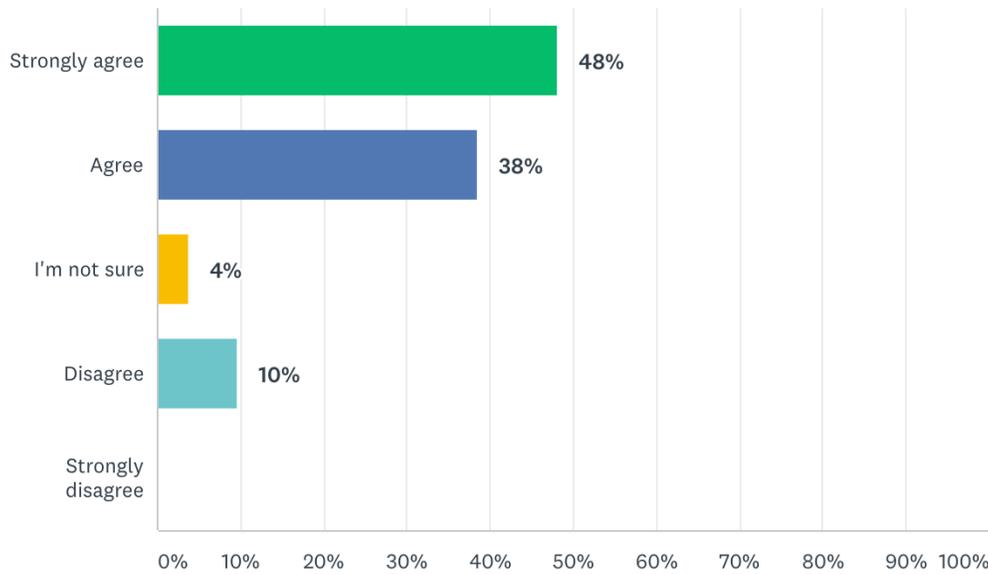
REPORTING. The focus of this survey section was on internal and external policies and procedures for various stakeholders. When asked about their organization’s **internal policies/procedures for staff** on how and when to report sexual violence/abuse against participants with I/DD (e.g., flow charts that detail who to notify, when, and how), the vast majority (86%) of day treatment providers agreed or strongly agreed that those policies/procedures were in place. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 1.7 with a standard deviation of 0.9. When asked to provide specific examples, many providers noted internal policies, state guidelines, or supervisor contacts as the main resource for reporting. Some notable mentions included reporting protocols specific to sexual violence/abuse incidents and chain of command flowcharts.

Figure 18. Percentage of day treatment providers with internal parent policies/ procedures for how and when to report sexual violence/abuse



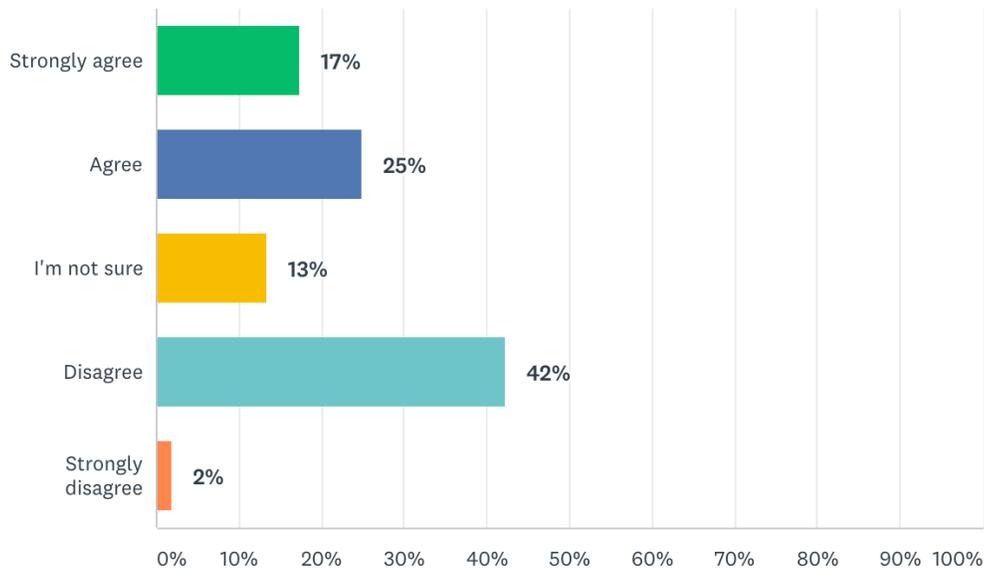
When asked about providing information about **internal policies/procedures for parents** on how and when to report sexual violence/abuse against participants with I/DD (e.g., tip sheet provided to parents), only a little more than one third (38%) of day treatment providers agreed or strongly agreed that those policies/procedures were being provided. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 2.9 with a standard deviation of 1.1. When asked to provide specific examples, many providers noted supplying copies of internal policies to parents.

Figure 17. Percentage of day treatment providers with internal staff policies/ procedures for how and when to report sexual violence/abuse



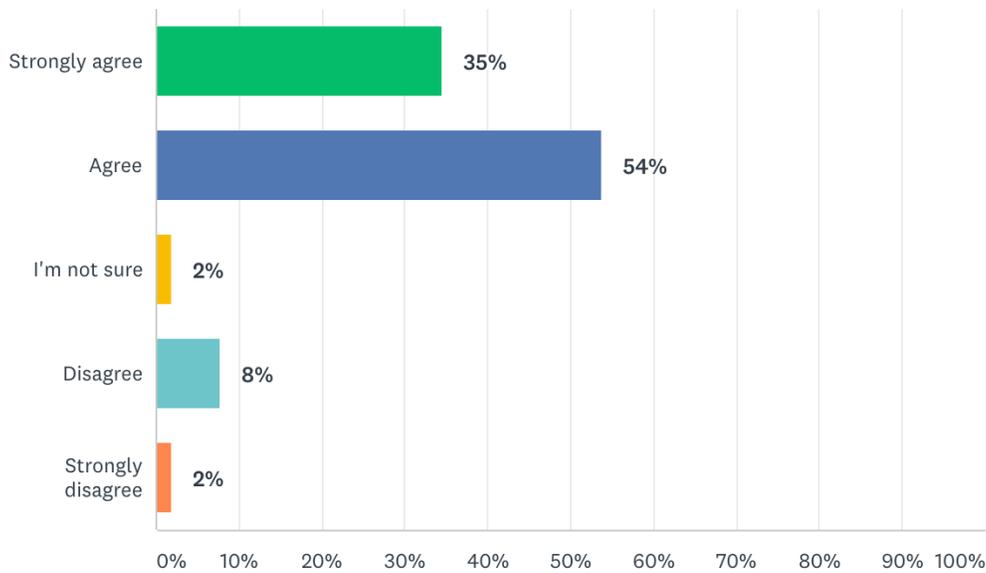
When asked about their organization’s **internal policies/procedures for participants with I/DD** on how and when to report sexual violence/abuse (e.g., visual aids written in clear, simple language), less than half (42%) of day treatment providers agreed or strongly agreed that those policies/procedures were being provided. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 2.9 with a standard deviation of 1.2. When asked to provide specific examples, many providers noted supplying copies of internal policies to participants without mentioning specific modifications for individuals with I/DD. No type of training or referrals for participants were noted.

Figure 19. Percentage of day treatment providers with internal participant policies/ procedures for how and when to report sexual violence/abuse



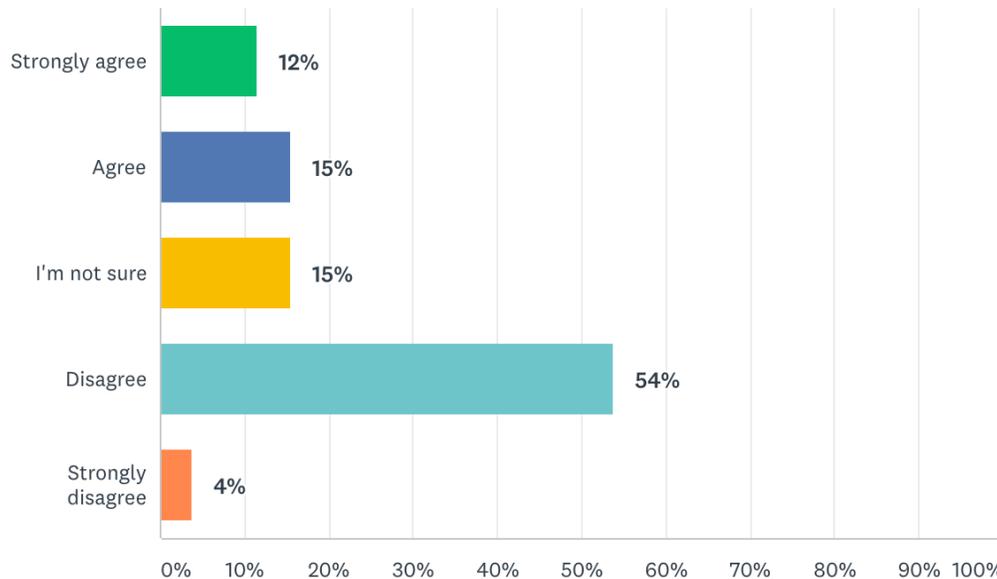
When asked about **staff trainings on how and when to report sexual violence/abuse** against participants with I/DD (e.g., in-person annual training on mandatory reporting), the vast majority (89%) of day treatment providers agreed or strongly agreed that those trainings were being provided. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 1.9 with a standard deviation of 0.9.

Figure 20. Percentage of day treatment providers with staff trainings on how and when to report sexual violence/abuse against individuals with I/DD



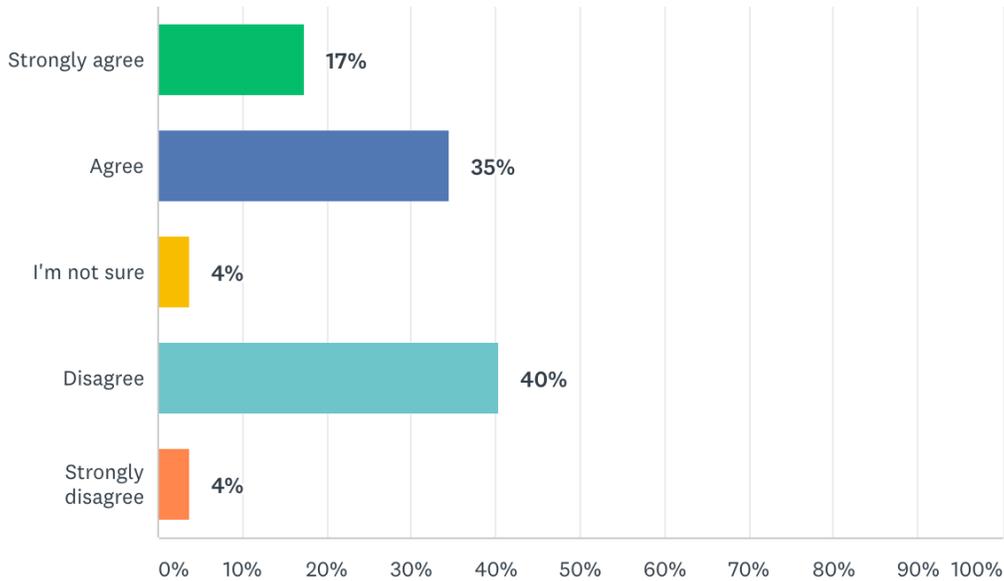
When asked about **parent trainings on how and when to report sexual violence/abuse** against participants with I/DD, less than one third (27%) of day treatment providers agreed or strongly agreed that those trainings were being provided. On a scale from 1 =strongly agree to 5 = strongly disagree, the mean rating was 3.2 with a standard deviation of 1.1.

Figure 21. Percentage of day treatment providers with parent trainings on how and when to report sexual violence/abuse against individuals with I/DD



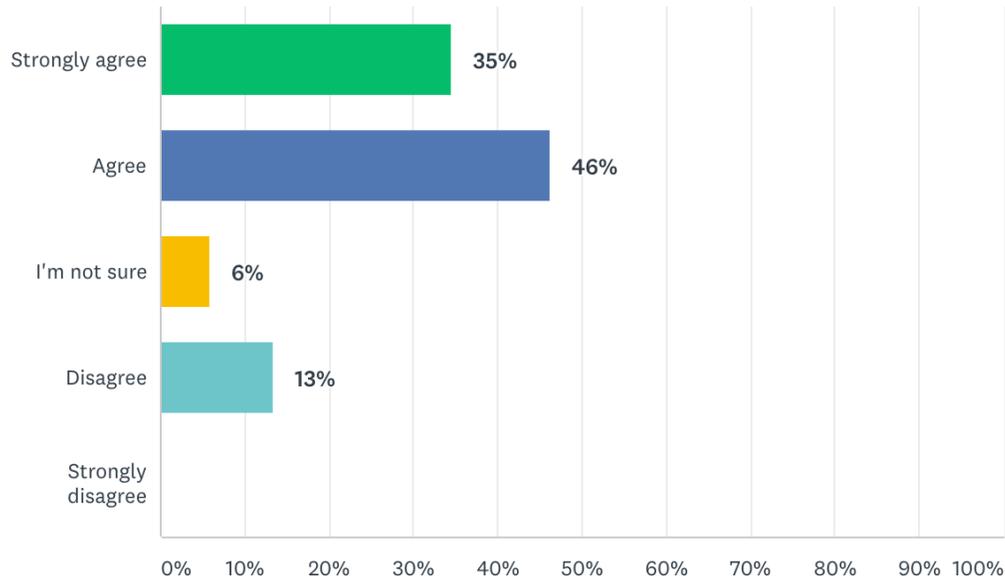
When asked about **participant trainings on how and when to report sexual violence/abuse** (e.g., training on appropriate vs. inappropriate touch or how to report abuse), about half (52%) of day treatment providers agreed or strongly agreed that those trainings were being provided. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 2.8 with a standard deviation of 1.2.

Figure 22. Percentage of day treatment providers with participant trainings on how and when to report sexual violence/abuse



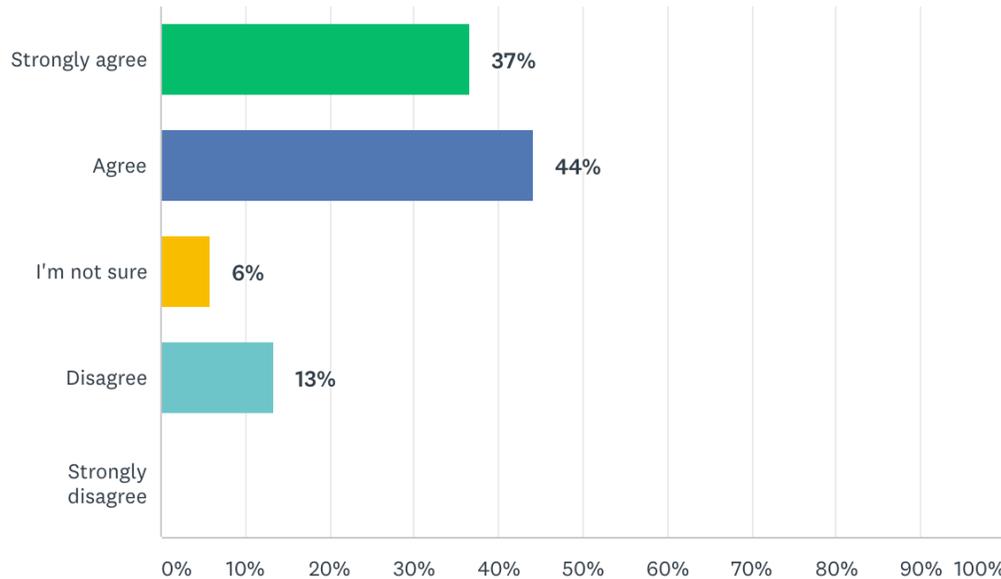
TRACKING. The focus of this survey section was on data recording of sexual violence/abuse against individuals with I/DD. While consistent terminology and detailed data management policies and procedures are critical, the current question intended to establish minimal data recording practices. When asked about their organization’s **internal process for recording data on allegations of sexual violence/abuse** against participants with I/DD, the vast majority (81%) of day treatment providers agreed or strongly agreed that such a process was in place. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 2.0 with a standard deviation of 1.0.

Figure 23. Percentage of day treatment providers with internal process for recording data on allegations of sexual violence/abuse



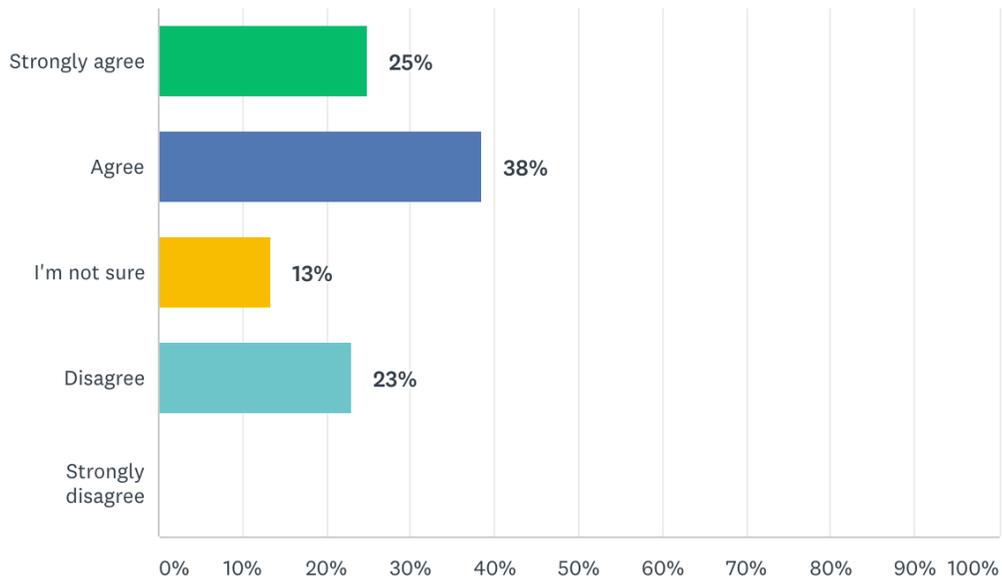
When asked about their organization’s **internal process for recording data on incidents** of sexual violence/abuse against participants with I/DD, the vast majority (81%) of day treatment providers agreed or strongly agreed that such a process was in place. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 1.9 with a standard deviation of 1.0.

Figure 24. Percentage of day treatment providers with internal process for recording data on incidents of sexual violence/abuse



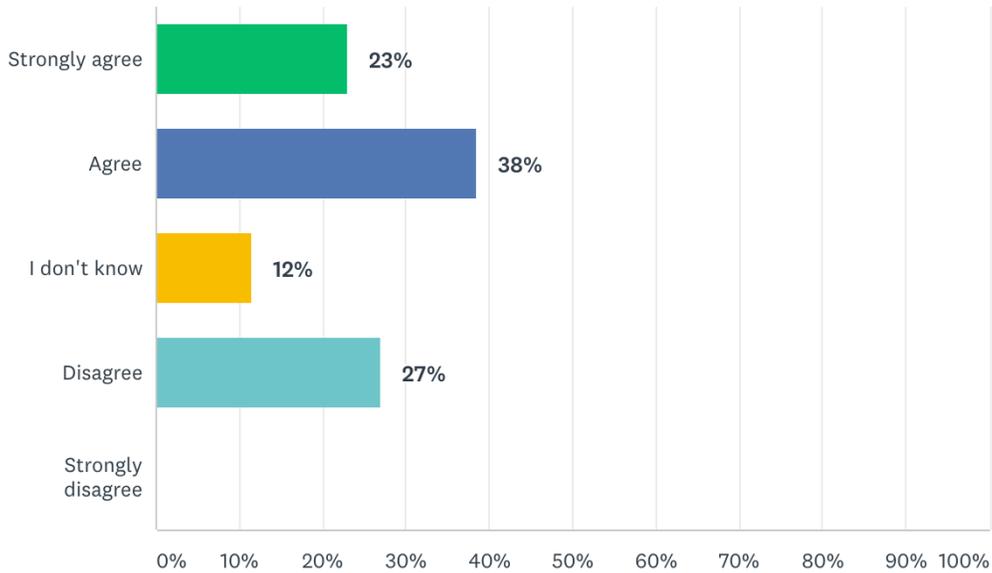
MONITORING. The focus of this survey section was on the extent to which an external entity ensures the organization’s compliance with established policies and procedures related to sexual violence/abuse against individuals with I/DD. When asked if an external authoritative body ensures their organization has established **policies/procedures to reduce the risk** of sexual violence/abuse against participants with I/DD, the majority (63%) of day treatment providers agreed or strongly agreed that this was the case. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 2.3 with a standard deviation of 1.1.

Figure 25. Percentage of day treatment providers with an external authoritative body that ensures policies/procedures to reduce risk for sexual violence/abuse are established



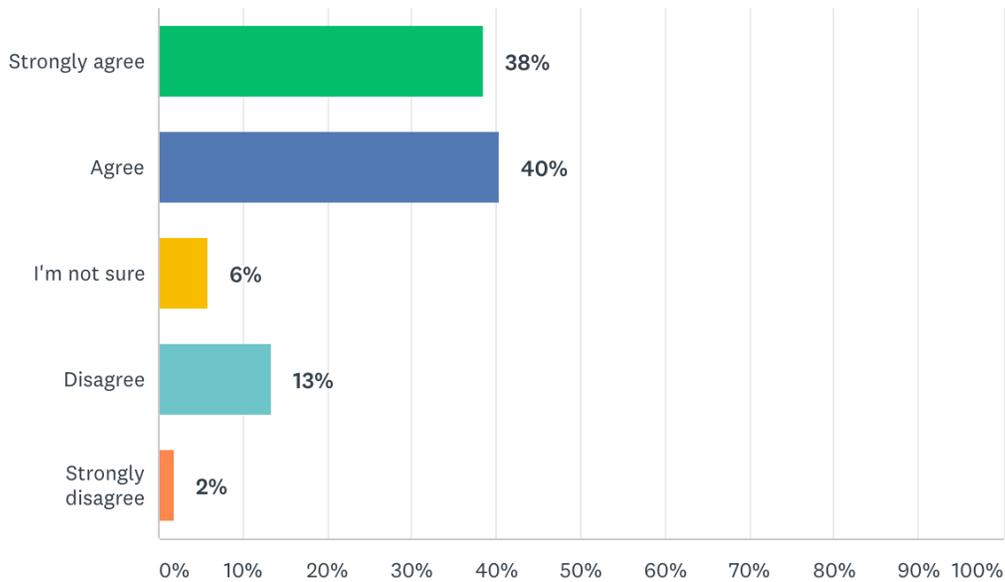
When asked if an external authoritative body verifies that their organization **implements these established policies/procedures**, the majority (61%) of day treatment providers agreed or strongly agreed that this was the case. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 2.4 with a standard deviation of 1.1. When asked to name this external authority, the most frequent response was the Department of Economic Security’s Division for Developmental Disabilities (DDD) and their quality assurance.

Figure 26. Percentage of day treatment providers with an external authoritative body that verifies established policies/procedures are implemented



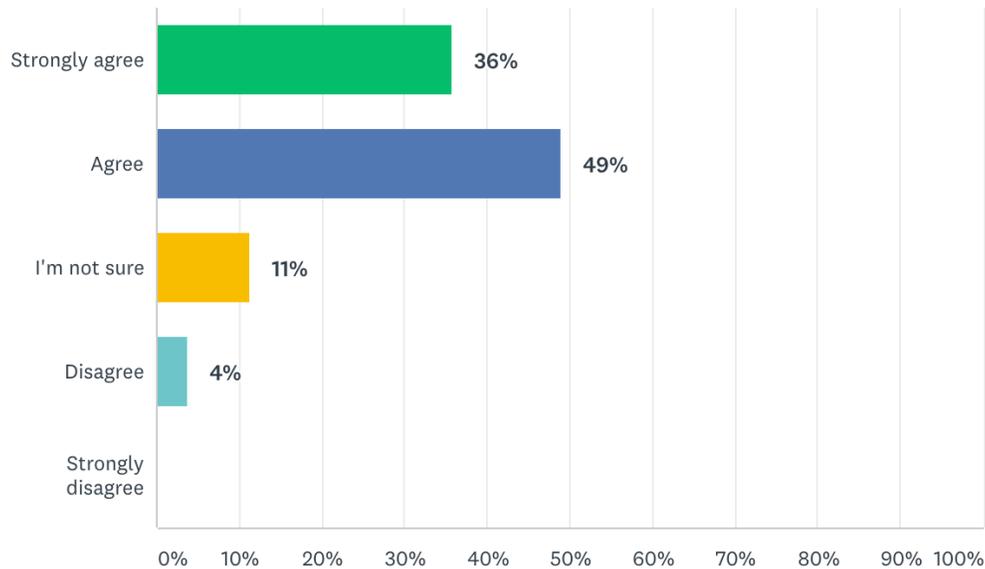
When asked if an external authoritative body is responsible for **following up on what has been done and what is coming next following a suspected incident**, the majority (78%) of day treatment providers agreed or strongly agreed that this was the case. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 2.0 with a standard deviation of 1.1.

Figure 27. Percentage of day treatment providers that rely on an external authority to follow up and determine what comes next after suspected incident of sexual violence/abuse



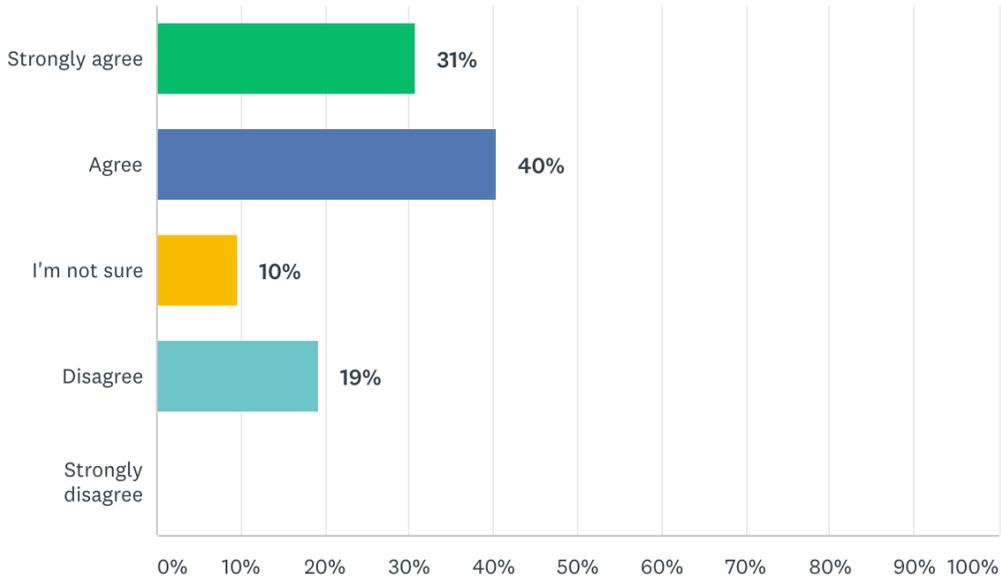
When asked if **participants with I/DD and their families know who to contact** if they believe the organization is being negligent or not following best practices, the majority (85%) of day treatment providers agreed or strongly agreed that this was the case. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 1.8 with a standard deviation of 0.8.

Figure 28. Percentage of day treatment providers with participants with I/DD and families that know who to contact if they believe their organization is negligent or not following best practices



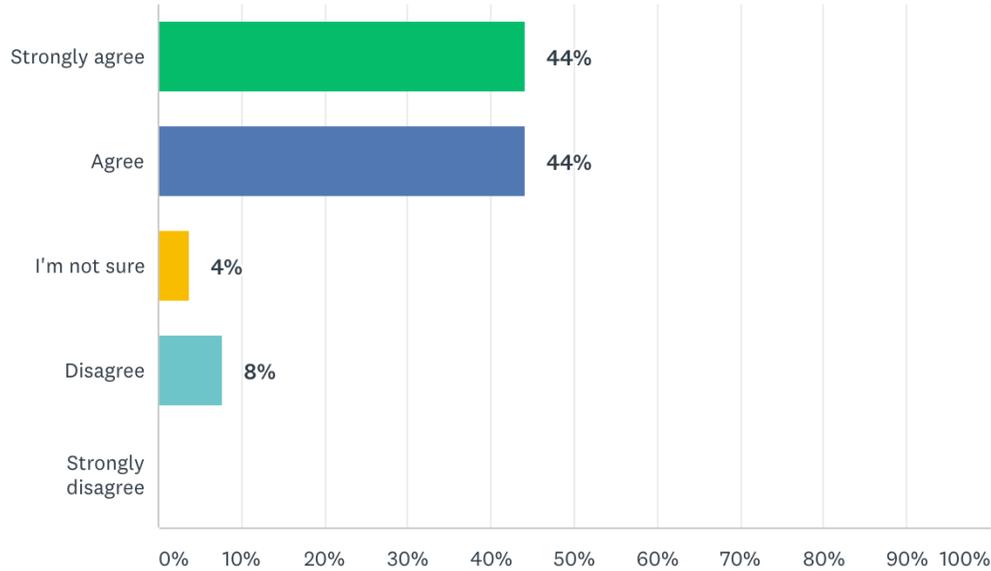
PREVENTION. The focus of this survey section was to determine general prevention efforts and the number of providers using a tiered approach to prevention. The latter was detailed in the *State of the Research* (Kurz et al., 2020) section recommending clearly delineated primary and secondary prevention strategies that differentiate between universal (i.e., all individuals with I/DD and caregivers) and targeted (i.e., high-risk individuals with I/DD and caregivers) strategies. When asked if their organization **actively engages in work to prevent sexual violence/abuse against participants with I/DD**, the majority (71%) of day treatment providers agreed or strongly agreed that this was the case. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 1.8 with a standard deviation of 0.8. When asked to provide specific examples, the most frequent examples included regular trainings (e.g., Article 9) and policy reviews, though without specifying the frequency. Some notable mentions included annual trainings for staff and participant’s relatives, as well as a mandatory team approach (i.e., two staff members per participant).

Figure 29. Percentage of day treatment providers that actively engage in work to prevent sexual violence/abuse against participants with I/DD



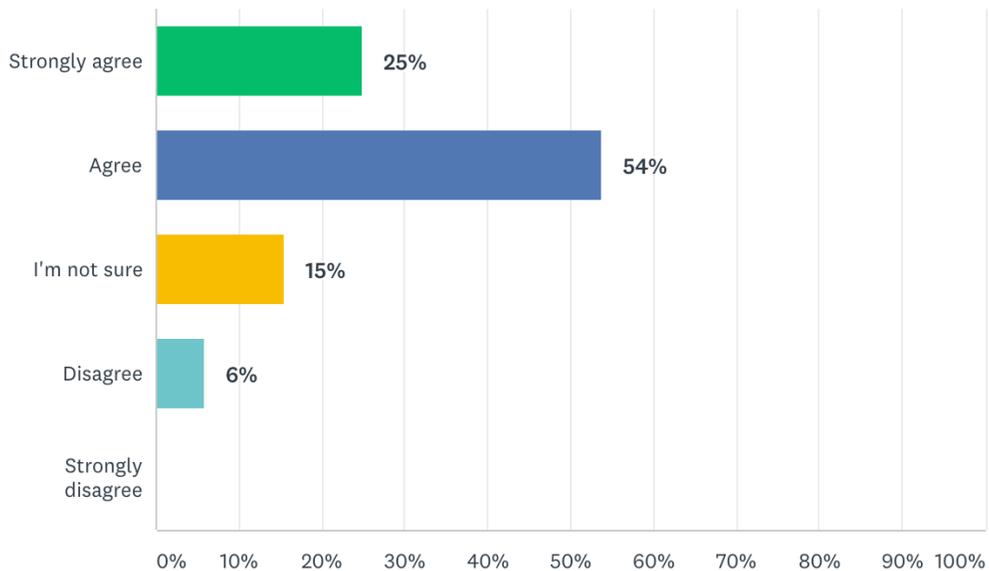
When asked if the **prevention of sexual violence/abuse against participants with I/DD is viewed as a key responsibility**, the majority (88%) of day treatment providers agreed or strongly agreed. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 1.8 with a standard deviation of 0.9.

Figure 30. Percentage of day treatment providers that view prevention of sexual violence/abuse against participants with I/DD as a key responsibility



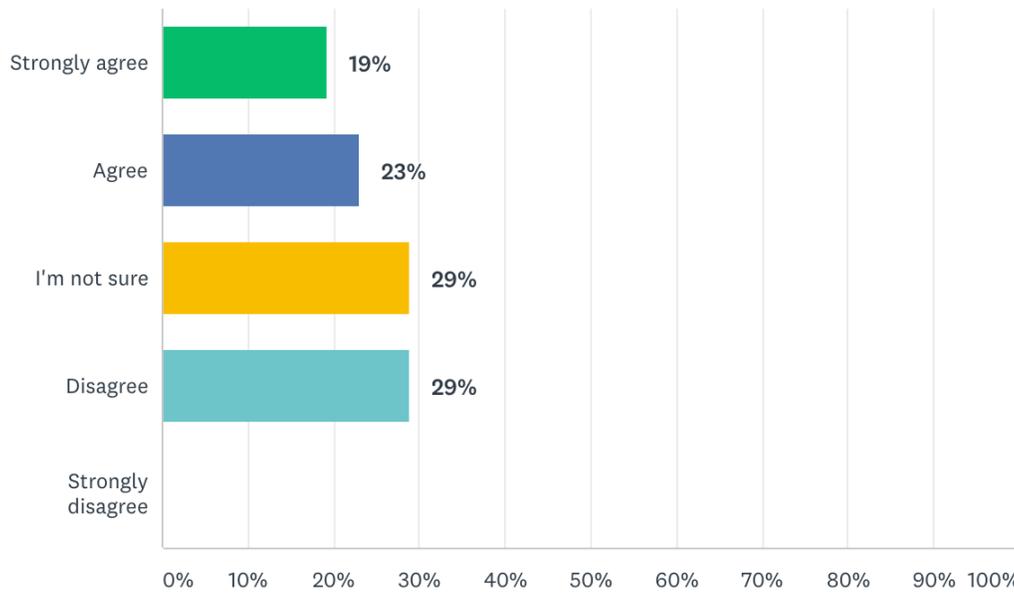
When asked if their organization is **aware of best practices for preventing sexual violence/abuse against participants with I/DD**, the majority (79%) of day treatment providers agreed or strongly agreed. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 2.0 with a standard deviation of 0.8.

Figure 31. Percentage of day treatment providers aware of best practices for preventing sexual violence/abuse against participants with I/DD



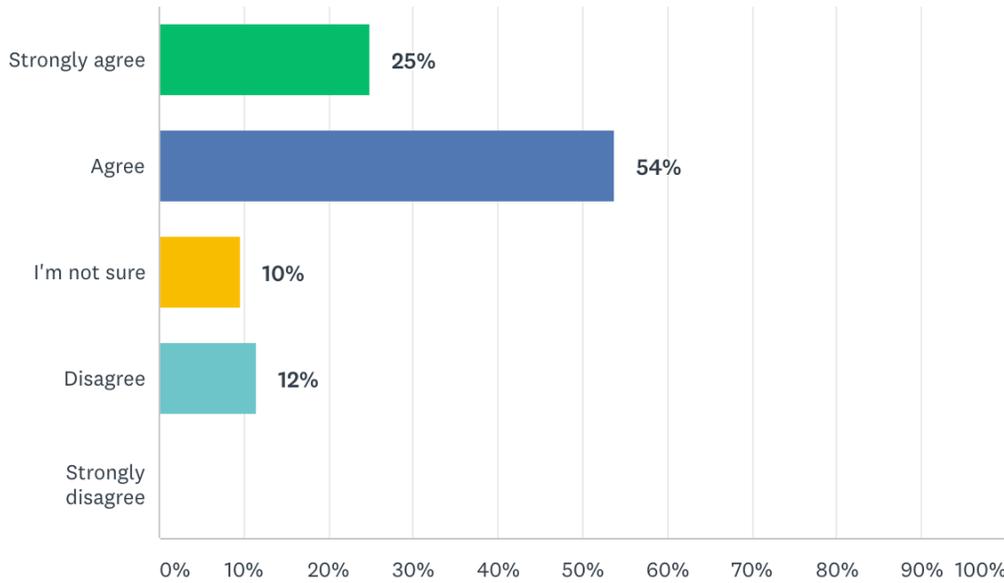
When asked if their organization uses a **tiered approach to prevention** (i.e., universal prevention, targeted prevention for high-risk groups, prevention of re-victimization for individuals with prior experience of sexual violence/abuse), less than half (42%) of day treatment providers agreed or strongly agreed that such an approach was in place. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 2.7 with a standard deviation of 1.1.

Figure 32. Percentage of day treatment providers with a tiered approach to sexual violence/abuse against participants with I/DD



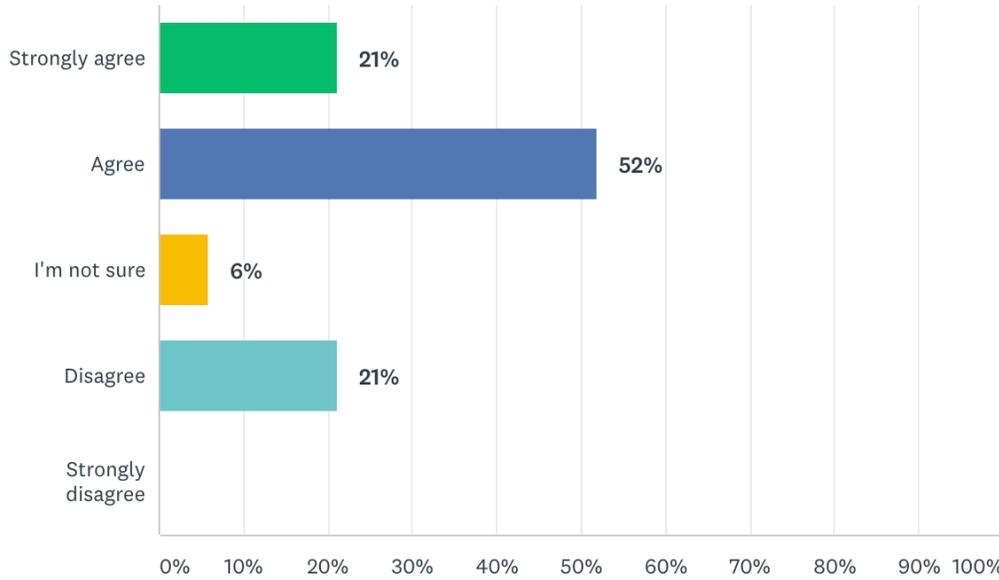
When asked if their organization’s prevention methods include **trainings and policies informed by best practices and empirical data**, the majority (79%) of day treatment providers agreed or strongly agreed that such an approach was in place. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 2.1 with a standard deviation of 0.9.

Figure 33. Percentage of day treatment providers with trainings and policies informed by best practices and empirical data



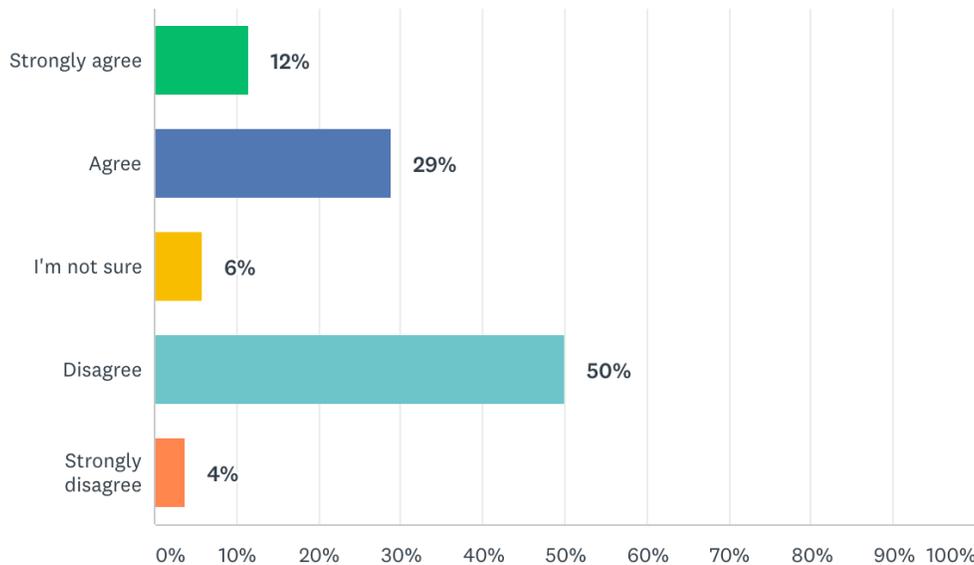
When asked if their organization **trains staff on strategies to prevent sexual violence/abuse** against participants with I/DD, the majority (73%) of day treatment providers agreed or strongly agreed that they provided such trainings. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 2.3 with a standard deviation of 1.0.

Figure 34. Percentage of day treatment providers with staff trainings on strategies to prevent sexual violence/abuse against participants with I/DD



When asked if their organization **trains parents/caregivers on strategies to keep their loved ones with I/DD safe** from sexual violence/abuse, less than half (41%) of day treatment providers agreed or strongly agreed that they provided such trainings. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 3.1 with a standard deviation of 1.2.

Figure 35. Percentage of day treatment providers with parent trainings to keep their loved ones with I/DD safe



RESULTS FOR GROUP HOME PROVIDERS

The sample was almost evenly split between **administrators** (51%) and **owners** (49%) who provided residential group home services in **suburban** (44%) and **urban** (40%) settings. Many of those providers (42%) operated only **one or two group homes**. The average number of group homes was 4.4 with a range of 1 to 16 group homes. Based on the general information provided by respondents, the majority of group homes featured **mostly female staff members** with moderate to very high turnover (see Figures 36-38). The majority of providers served **between 1-5 residents** with I/DD split between male and female participants. Almost all group homes served **adults with I/DD** with some also serving teenagers (ages 12 to 18) and elderly adults (65 or older) with I/DD. While the majority of disability limitations noted were cognitive (96%), each group home provider served a wide a range of disabilities (see Figures 39-42).

Figure 36. Average staff size per facility

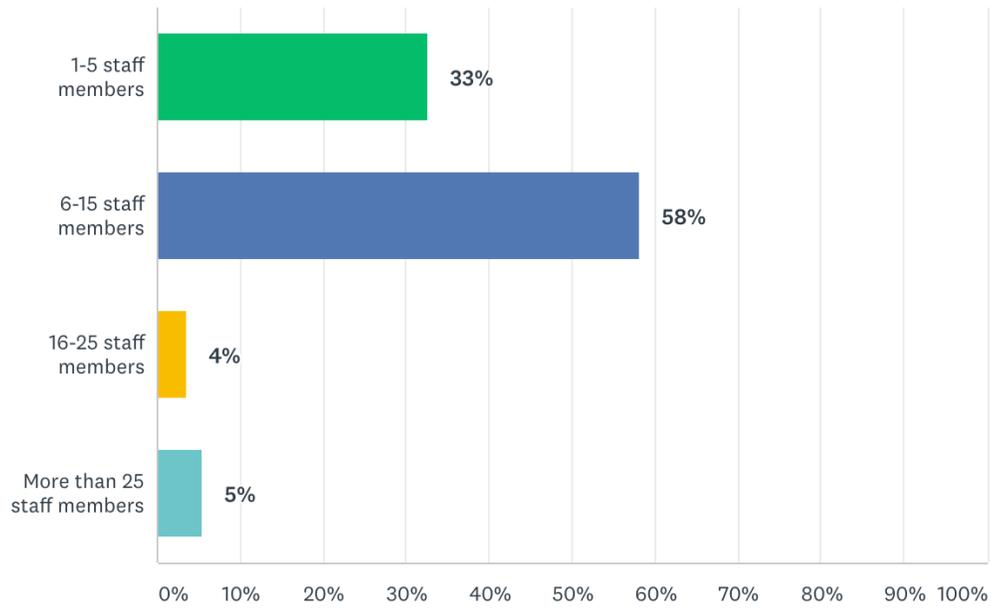


Figure 37. Gender ratio of staff

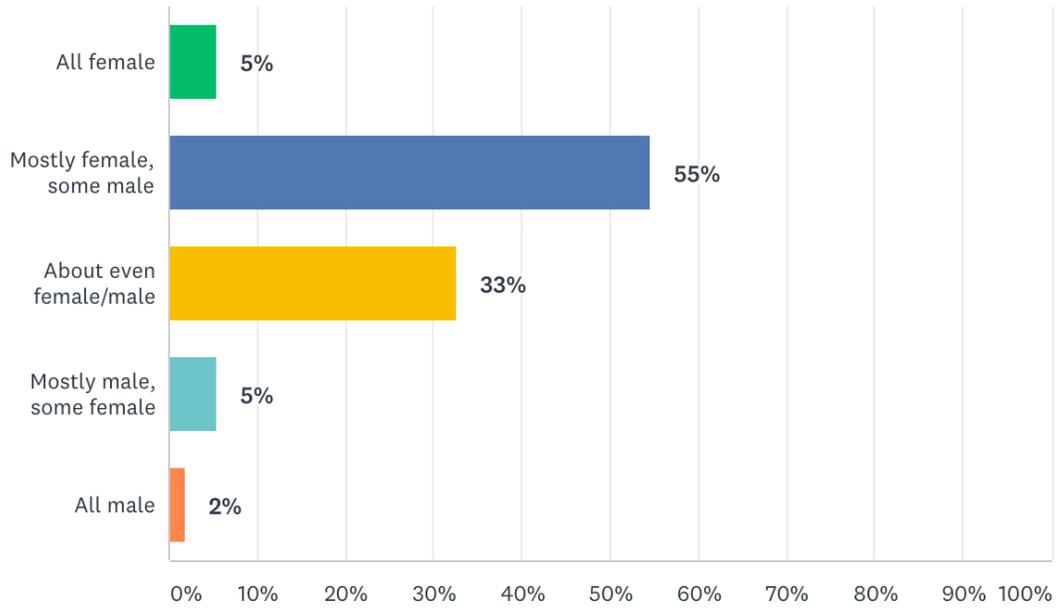


Figure 38. Estimated staff turnover

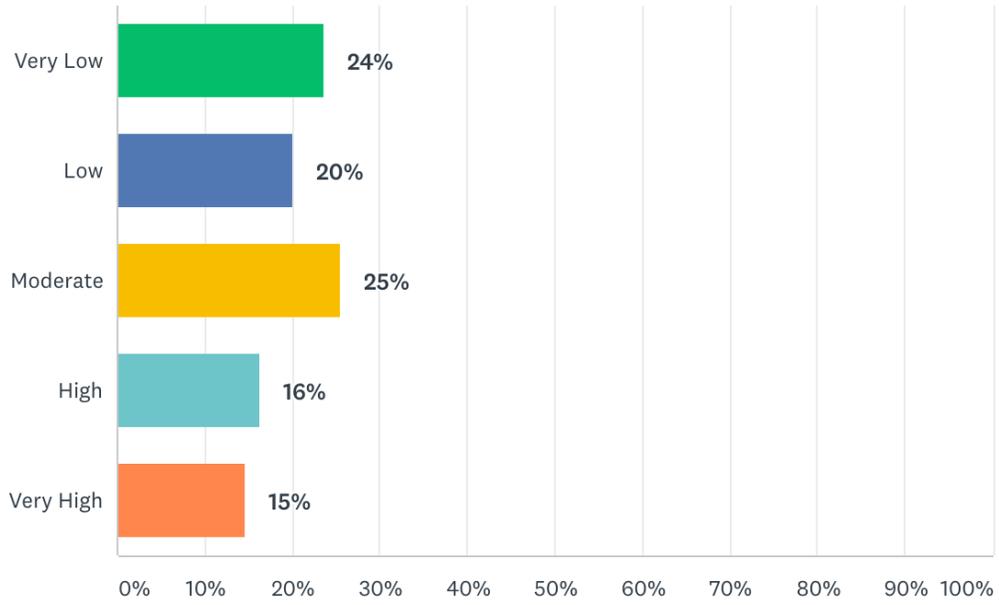


Figure 39. Average number of residents with I/DD per facility

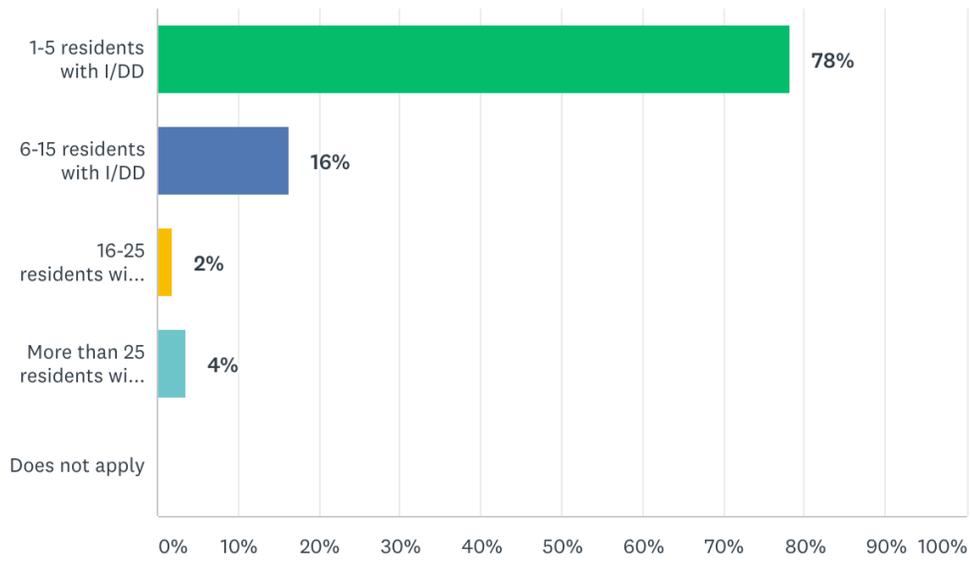


Figure 40. Gender ratio of residents with I/DD

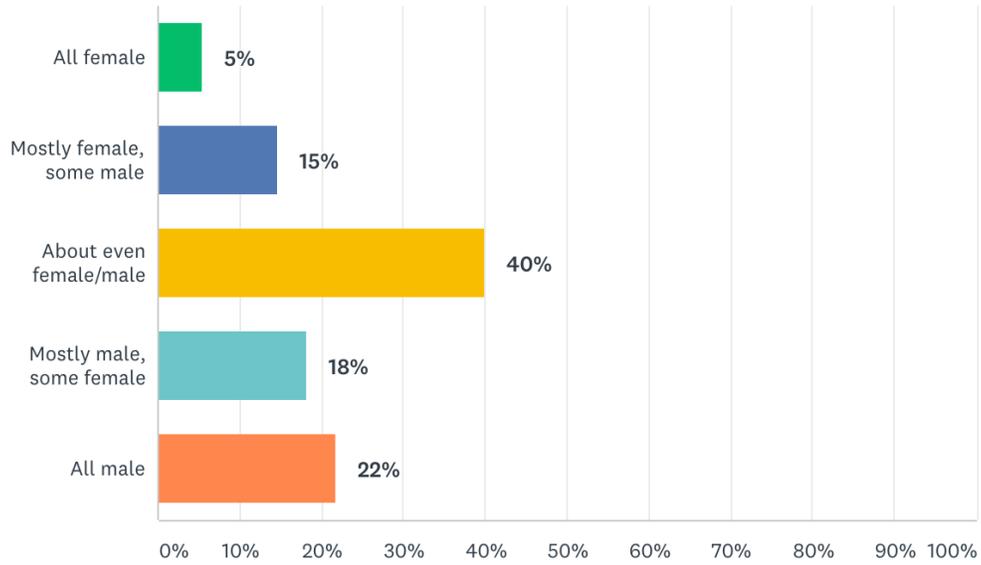


Figure 41. Age groups of participants with I/DD served

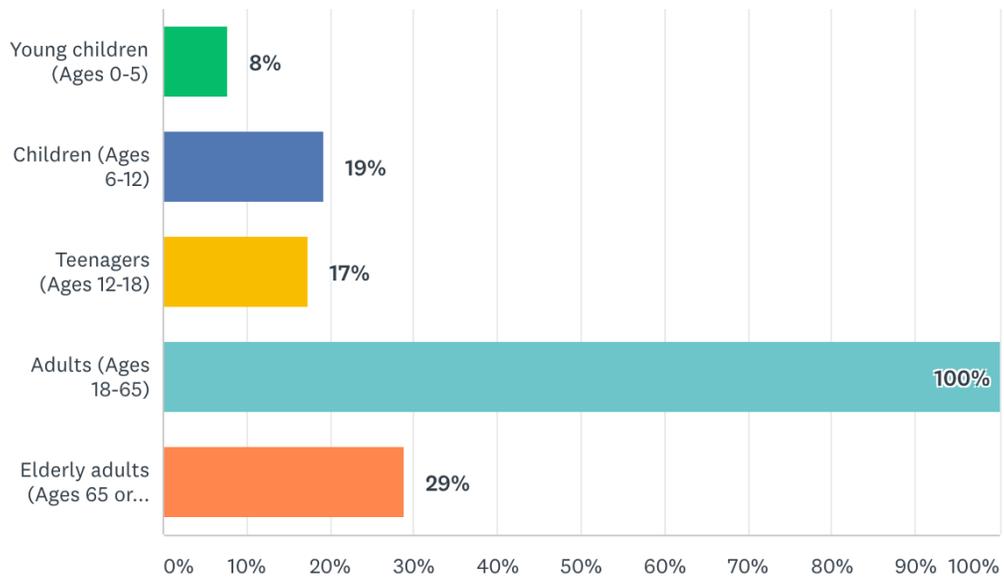
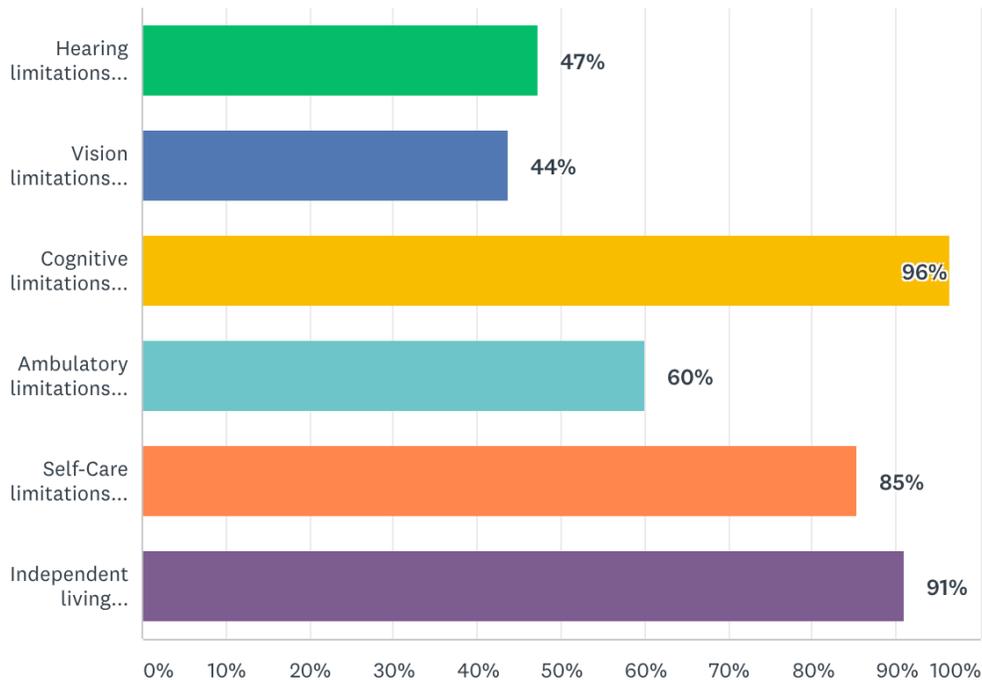


Figure 42. Disabilities served based on limitations



DETECTION. One of the key recommendations based on the research literature was the need to have policy and procedures in place that can **assess the risk** of sexual violence/abuse against individuals with I/DD [see 1.1-1.4]. Specific examples included **risk assessments** and universal **screening assessments** including audio computer-assisted self-interviews (ACASIs). The majority (77%) of day treatment providers agreed or strongly agreed that they had policies and procedures in place for determining the risk using such tools as risk assessments at intake or periodic screening (see Figure 8). On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 1.8 with a standard deviation of 1.0. When asked to provide specific tools, the most frequent examples included internal policies and background checks. Some notable mentions included monthly policy reviews and risk assessments at intake.

Figure 43. Percentage of group home providers with policies/procedures in place for determining the risk of sexual violence/abuse against residents with I/DD

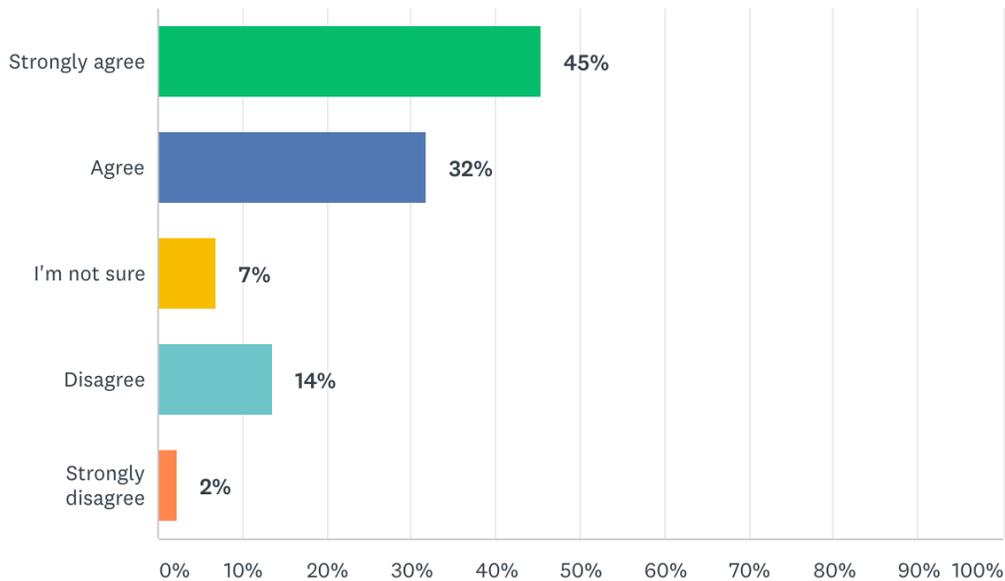
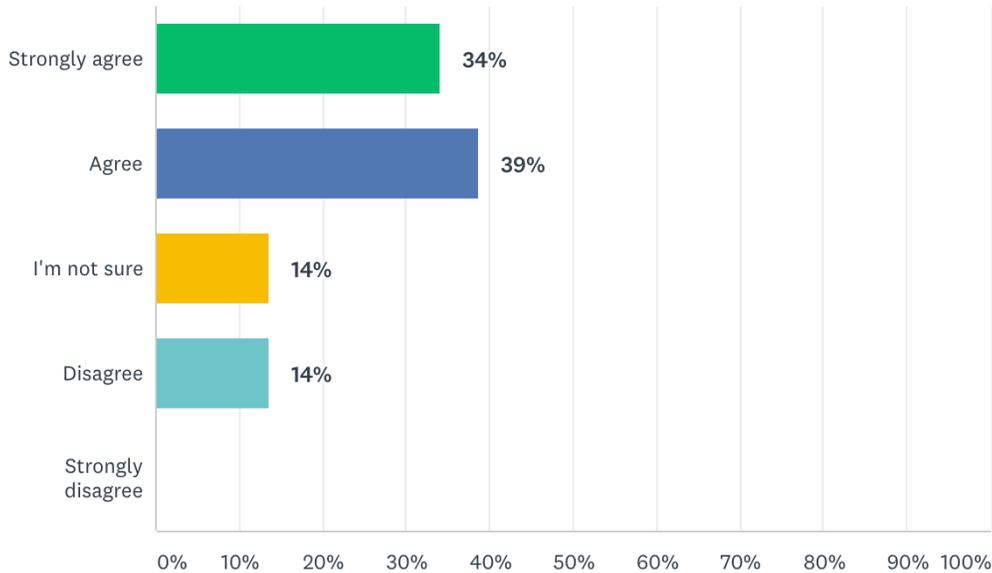


Figure 44. Word cloud based on key word frequencies



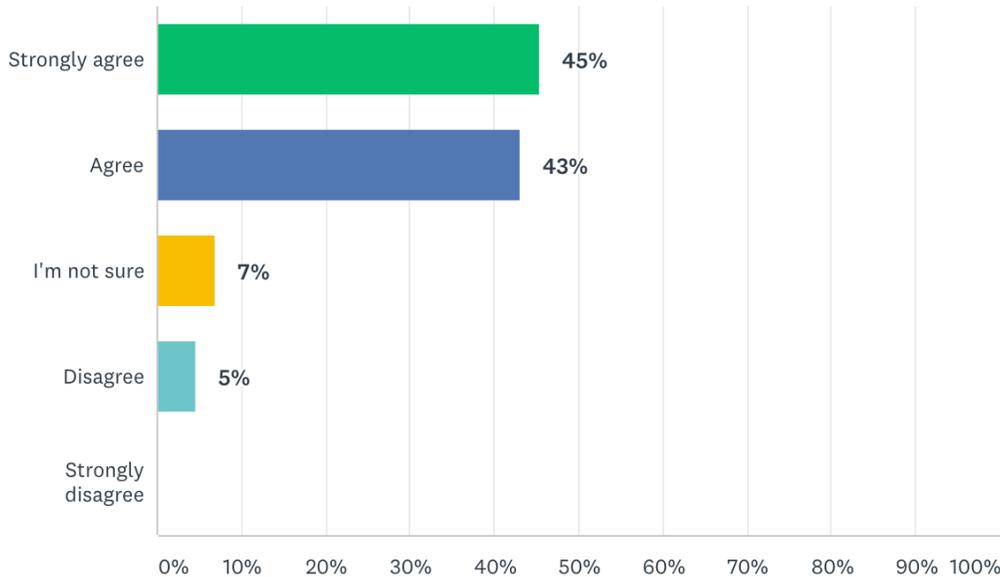
When asked about the presence of an **internal process for detecting** the presence of sexual violence/abuse against residents with I/DD (e.g., tip sheet with warning signs), the majority (73%) of group home providers agreed or strongly agreed that processes were in place. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 1.8 with a standard deviation of 0.9. When asked about specific examples, the majority of answers mentioned internal staff trainings. Some notable mentions included tip sheet, body charting when bathing, cameras in common areas, and frequent visits by upper management.

Figure 45. Percentage of group home providers with internal process for detecting the presence of sexual violence/abuser against residents with I/DD



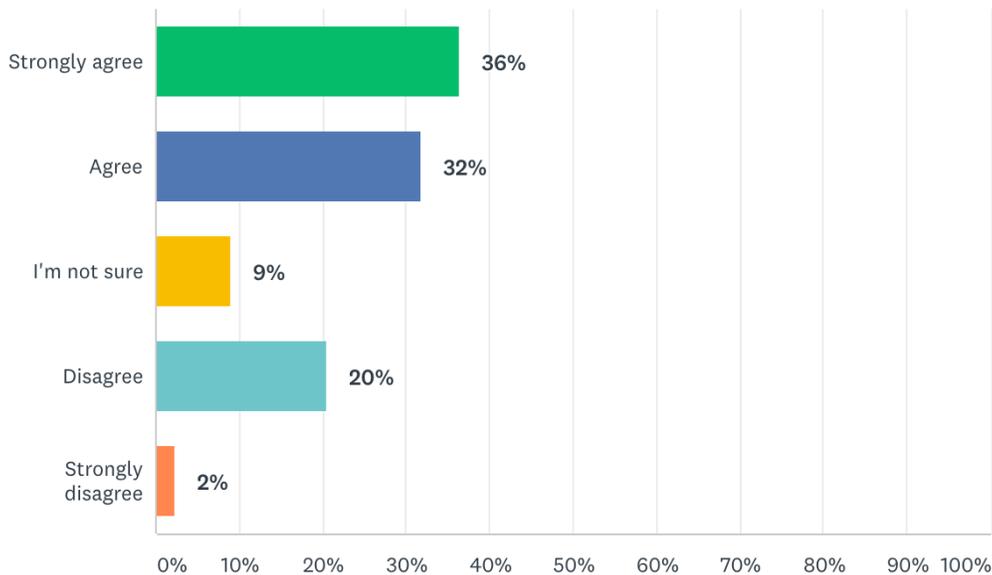
When asked about staff knowledge related to **risk factors** for sexual violence/abuse against residents with I/DD, the vast majority (88%) of group home providers agreed or strongly agreed that their staff was familiar with risk factors. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 1.7 with a standard deviation of 0.8.

Figure 46. Percentage of group home providers with staff knowledge about risk factors for sexual violence/abuse against residents with I/DD



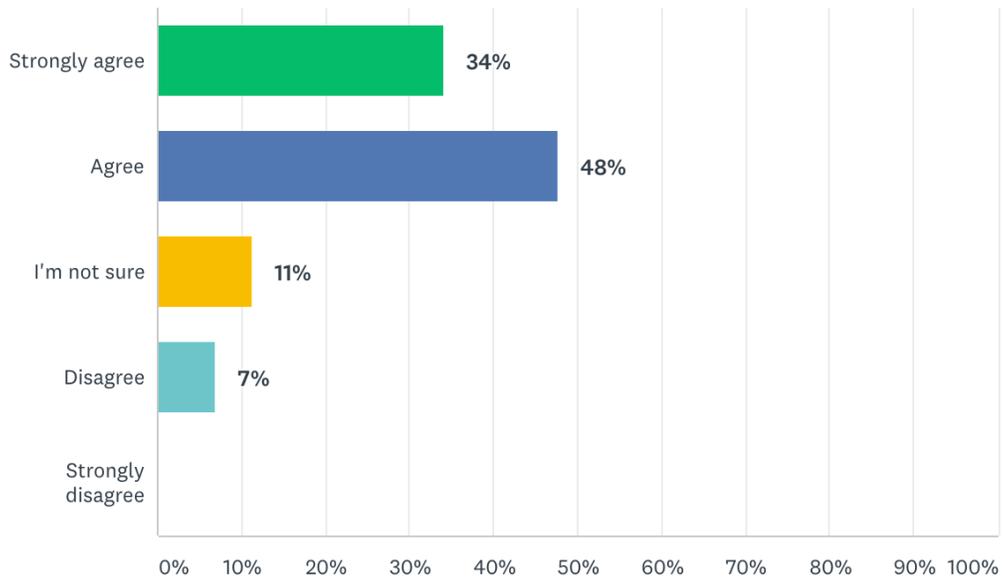
When asked about use of **screening or measurement tools to determine risk** for sexual violence/abuse against participants with I/DD, over half (68%) of group home providers agreed or strongly agreed that their organization used some type of measurement tool to determine risk. This finding appears to be at odds with earlier questions (see Figures 7 and 8) for which respondents indicated having risk assessments available. A possible explanation for this discrepancy is the focus on a “measurement tool” for purposes of assessing risk. As such, it appears that the term “risk assessment” noted earlier may have referred to an informal process (e.g., simple check list) rather than formal measurement tool (e.g., rating scale with psychometric properties including cut scores for risk levels). On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 2.0 with a standard deviation of 1.1.

Figure 47. Percentage of group home providers that use screening or measurement tools to determine risk of sexual violence/abuse against residents with I/DD



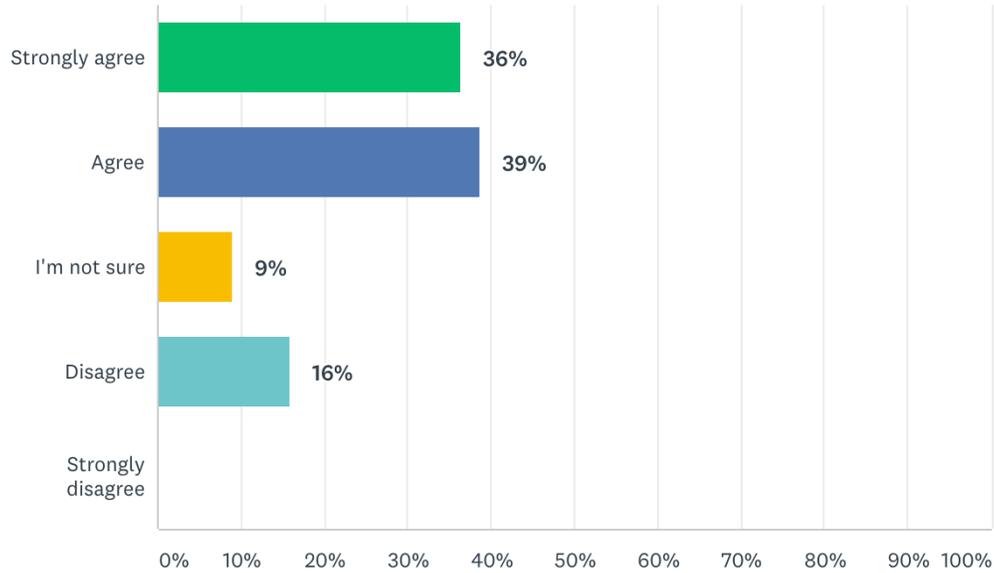
When asked about staff understanding of the risks involved when **asking individuals with I/DD about possible sexual violence/abuse**, the majority (82%) of group home providers agreed or strongly agreed that their staff was aware. As noted in the research literature, only trained professionals should question individuals with I/DD without any real or perceived threats of retaliation present (see 1.5). On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 1.8 with a standard deviation of 0.8.

Figure 48. Percentage of group home providers with staff that understands the risks involved with asking individuals with I/DD about possible sexual violence/abuse.



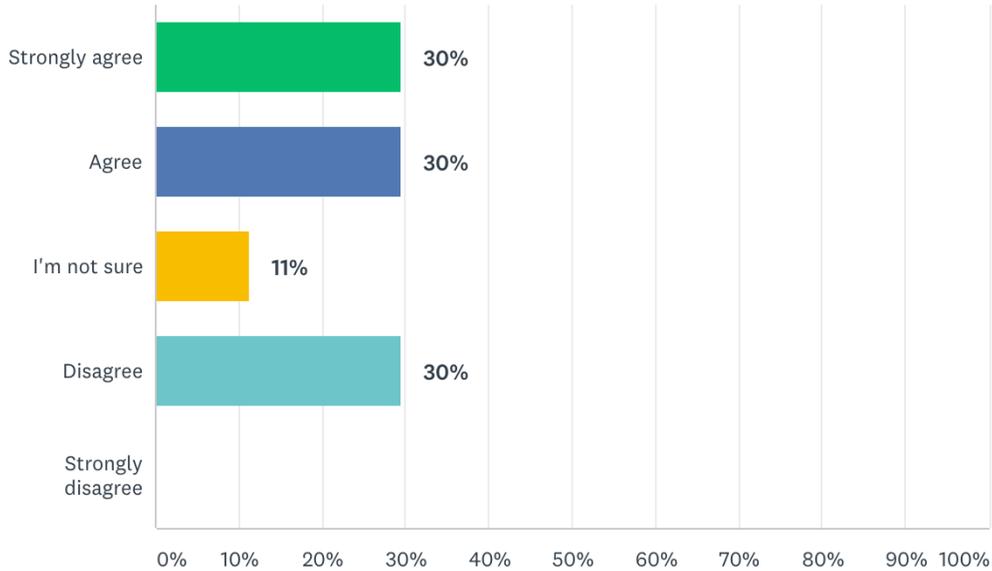
When asked about **staff trainings on risk factors** for sexual violence/abuse against residents with I/DD, the majority (75%) of group home providers agreed or strongly agreed their staff were trained. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 2.2 with a standard deviation of 1.1.

Figure 49. Percentages of group home providers with staff trainings on risk factors for sexual violence/abuse against residents with I/DD



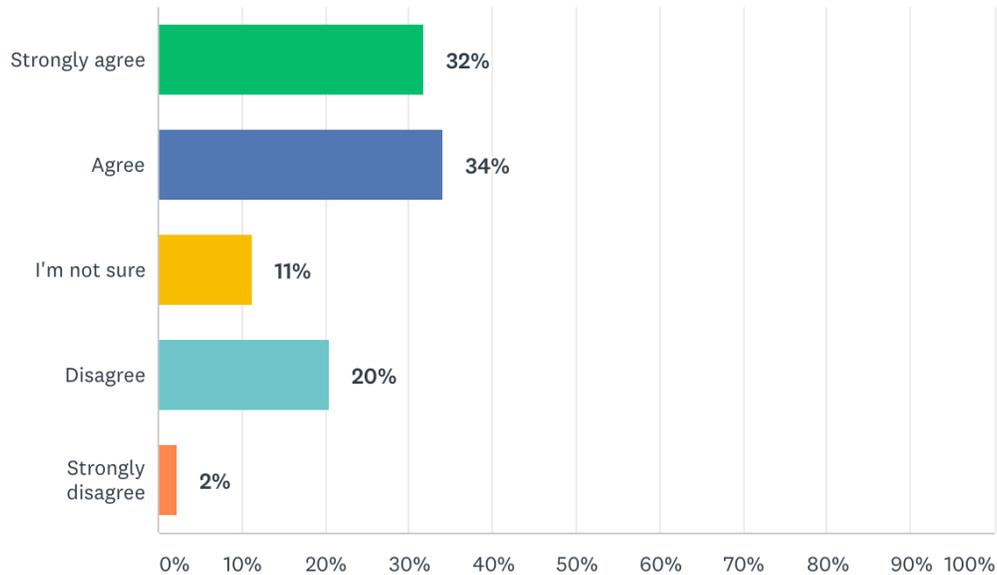
When asked about **staff trainings on screening or measurement tools** to determine the risk or presence of sexual violence/abuse against participants with I/DD, the majority (60%) of group home providers agreed or strongly agreed that their staff were trained. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 2.2 with a standard deviation of 1.2.

Figure 50. Percentage of group home providers with staff trainings on screening or measurement tools to determine the risk or presence of sexual violence/abuse against residents with I/DD



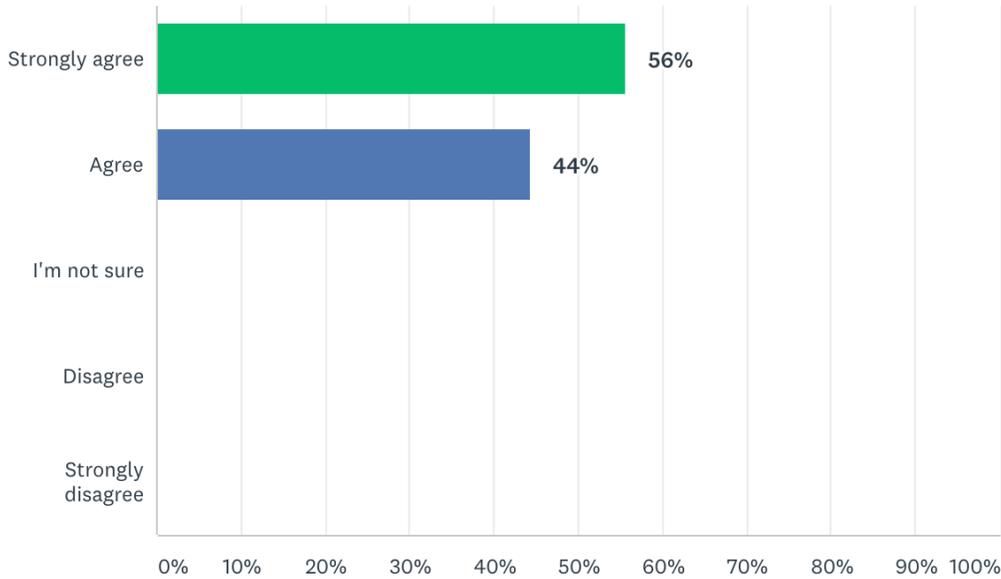
When asked about **staff trainings on the risks involved with asking individuals with I/DD about possible sexual violence/abuse**, the majority (66%) of group home providers agreed or strongly agreed that their staff were trained. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 2.1 with a standard deviation of 1.1.

Figure 51. Percentage of group home providers with staff trainings on the risks involved with asking individuals with I/DD about possible sexual violence/abuse



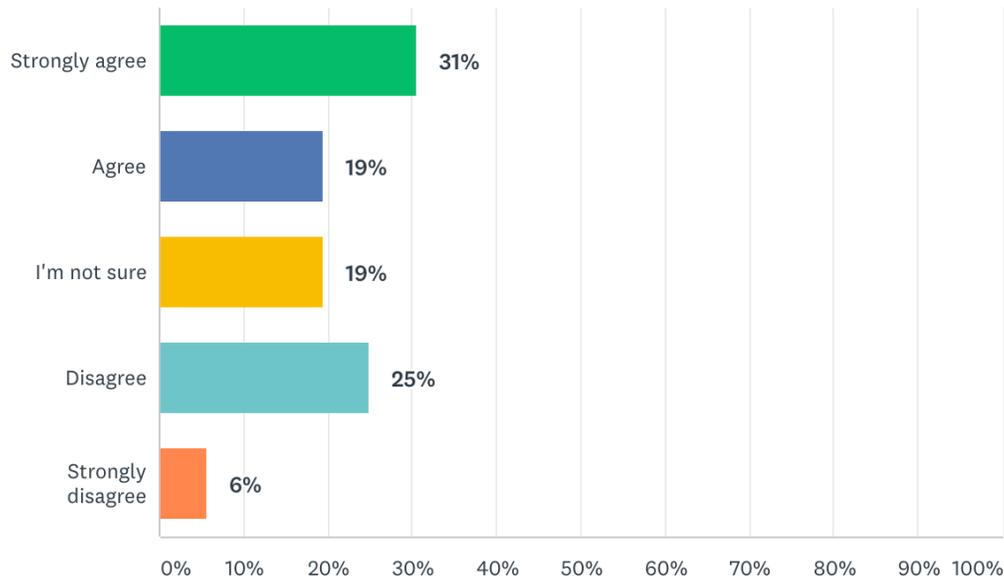
REPORTING. The focus of this survey section was on internal and external policies and procedures for various stakeholders. When asked about their organization’s **internal policies/procedures for staff** on how and when to report sexual violence/abuse against residents with I/DD (e.g., flow charts that detail who to notify, when, and how), all (100%) group home providers agreed or strongly agreed that those policies/procedures were in place. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 1.5 with a standard deviation of 0.5. When asked to provide specific examples, many providers noted internal policies, DDD, and 911 as the main resource for reporting. Some notable mentions included chain-of-command flowcharts and step-by-step protocols (i.e., protect resident, report to charge nurse, provide written statement, collect witness statements, secure any evidence, contact guardian and police).

Figure 52. Percentage of group home providers with internal staff policies/ procedures for how and when to report sexual violence/abuse



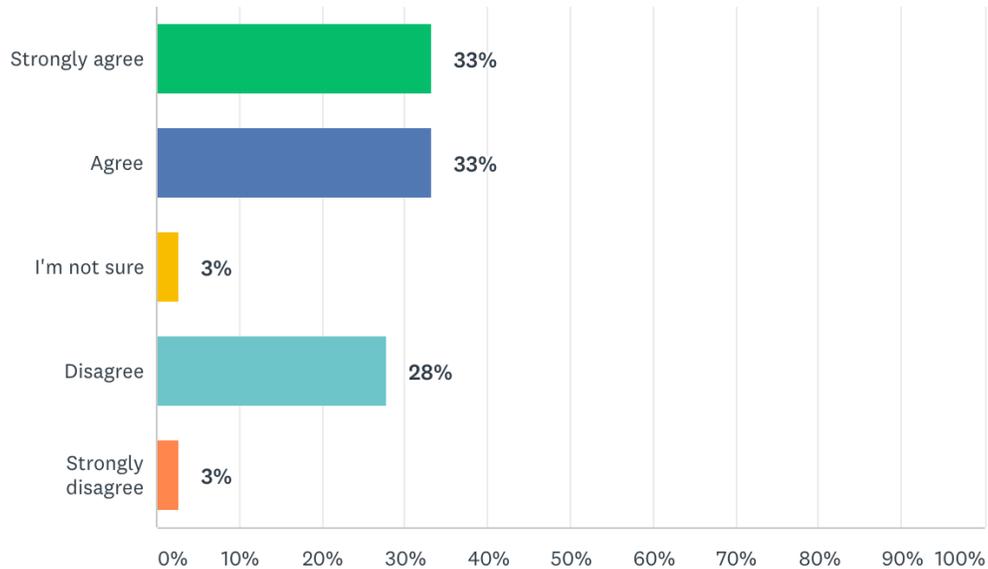
When asked about providing information about **internal policies/procedures for parents** on how and when to report sexual violence/abuse against residents with I/DD (e.g., tip sheet provided to parents), half (50%) of group home providers agreed or strongly agreed that those policies/procedures were being provided. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 2.5 with a standard deviation of 1.3. When asked to provide specific examples, many group home providers noted open lines of communication, supervisor contacts, and supplying copies of internal policies to parents.

Figure 53. Percentage of group home providers with internal parent policies/ procedures for how and when to report sexual violence/abuse



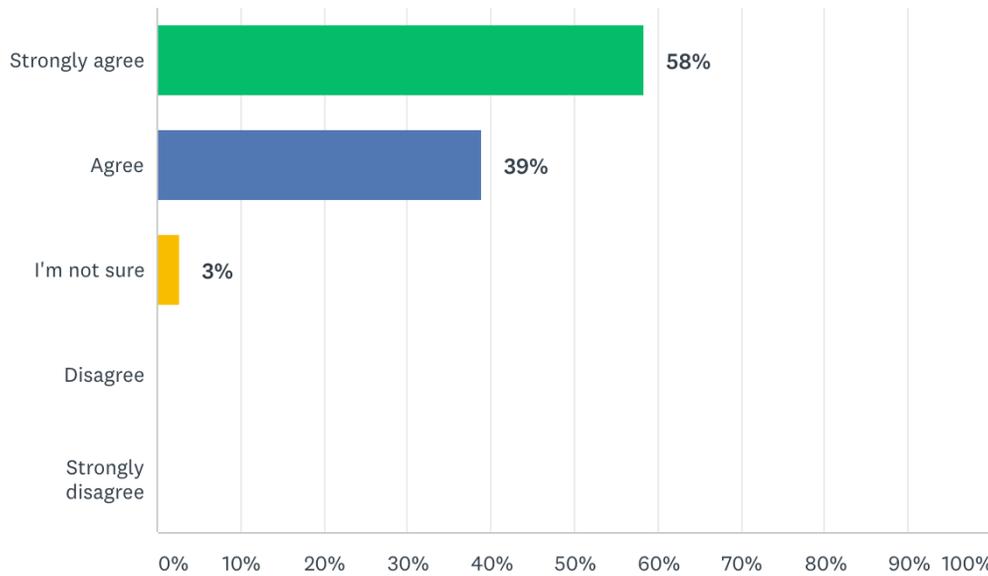
When asked about their organization’s **internal policies/procedures for residents with I/DD** on how and when to report sexual violence/abuse (e.g., visual aids written in clear, simple language), the majority (66%) of group home providers agreed or strongly agreed that those policies/procedures were being provided. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 2.2 with a standard deviation of 1.2. When asked to provide specific examples, many providers mentioned access to supervisors or management. A notable mention included an adapted version of a flowchart in simplified language.

Figure 54. Percentage of group home providers with internal resident policies/ procedures for how and when to report sexual violence/abuse



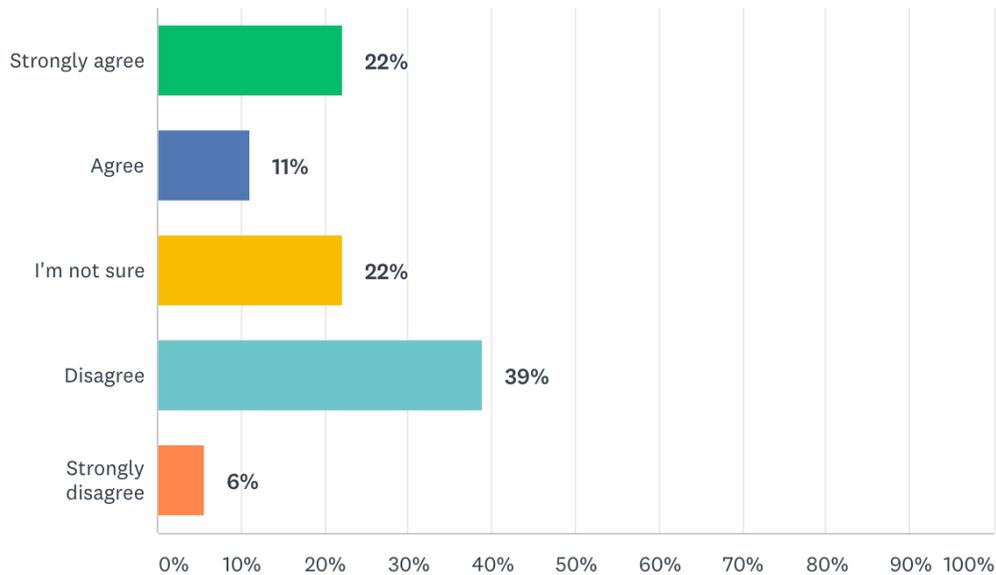
When asked about **staff trainings on how and when to report sexual violence/abuse** against residents with I/DD (e.g., in-person annual training on mandatory reporting), almost all (97%) group home providers agreed or strongly agreed that those trainings were being provided. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 1.5 with a standard deviation of 0.6.

Figure 55. Percentage of group home providers with staff trainings on how and when to report sexual violence/abuse against residents with I/DD



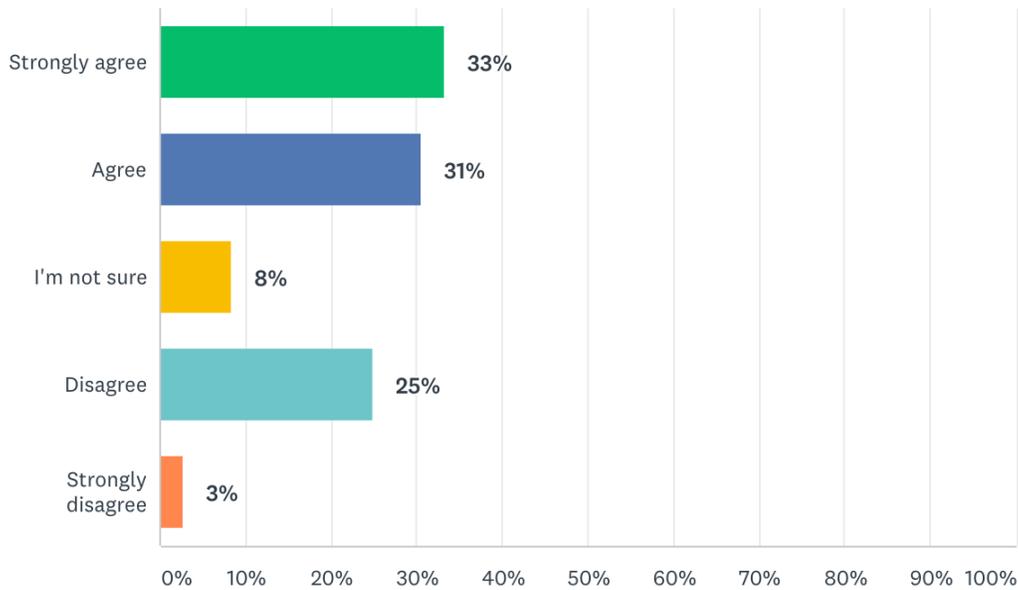
When asked about **parent trainings on how and when to report sexual violence/abuse** against residents with I/DD, one third (33%) of group home providers agreed or strongly agreed that those trainings were being provided. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 2.8 with a standard deviation of 1.3.

Figure 56. Percentage of group home providers with parent trainings on how and when to report sexual violence/abuse against residents with I/DD



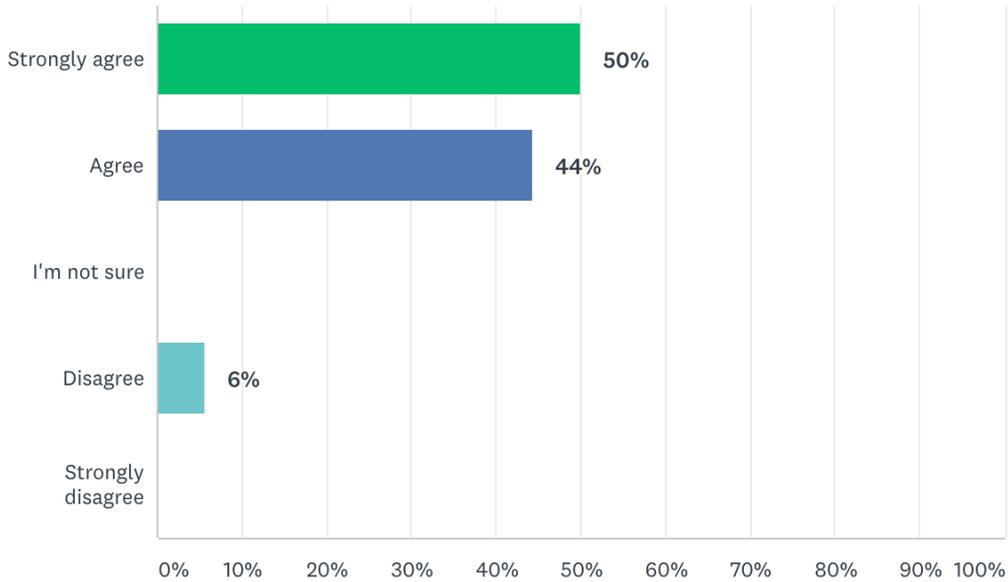
When asked about **resident trainings on how and when to report sexual violence/abuse** (e.g., training on appropriate vs. inappropriate touch or how to report abuse), the majority (64%) of group home providers agreed or strongly agreed that those trainings were being provided. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 2.2 with a standard deviation of 1.3.

Figure 57. Percentage of group home providers with resident trainings on how and when to report sexual violence/abuse



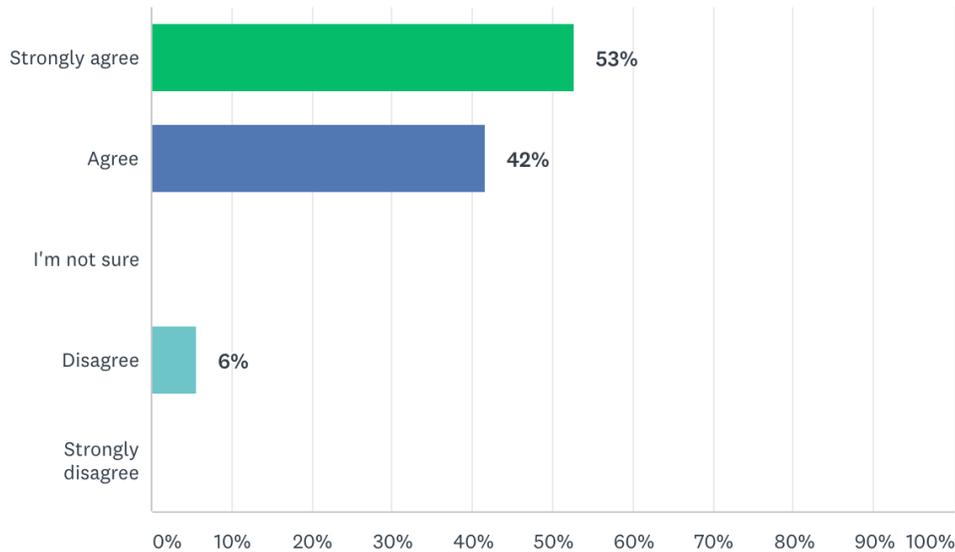
TRACKING. The focus of this survey section was on data recording of sexual violence/abuse against residents with I/DD. While consistent terminology and detailed data management policies and procedures are critical, the current question intended to establish minimal data recording practices. When asked about their organization’s **internal process for recording data on allegations of sexual violence/abuse against residents with I/DD**, the vast majority (94%) of group home providers agreed or strongly agreed that such a process was in place. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 1.5 with a standard deviation of 0.7.

Figure 58. Percentage of group home providers with internal process for recording data on allegations of sexual violence/abuse



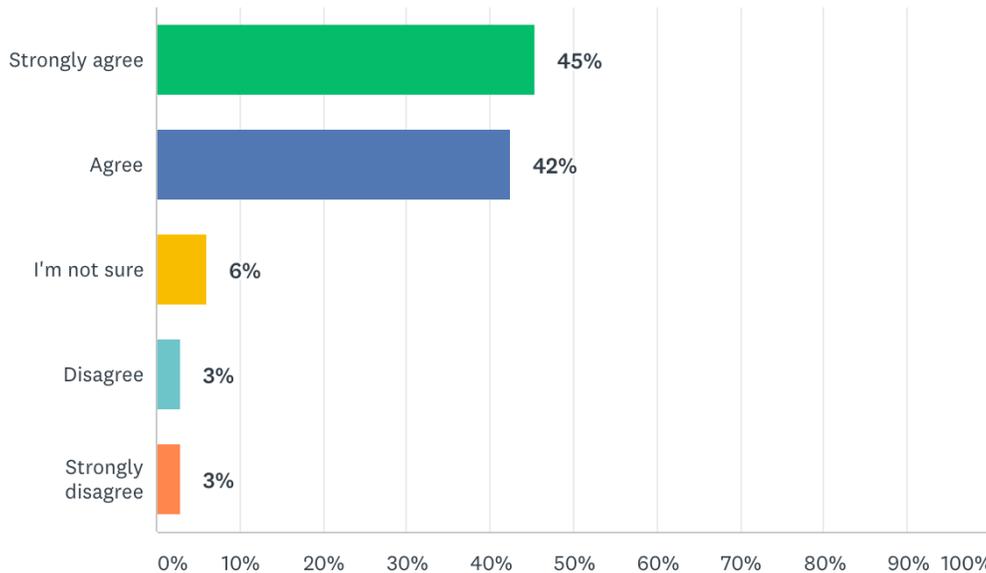
When asked about their organization’s **internal process for recording data on incidents** of sexual violence/abuse against residents with I/DD, the vast majority (95%) of group home providers agreed or strongly agreed that such a process was in place. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 1.5 with a standard deviation of 0.7.

Figure 59. Percentage of group home providers with internal process for recording data on incidents of sexual violence/abuse



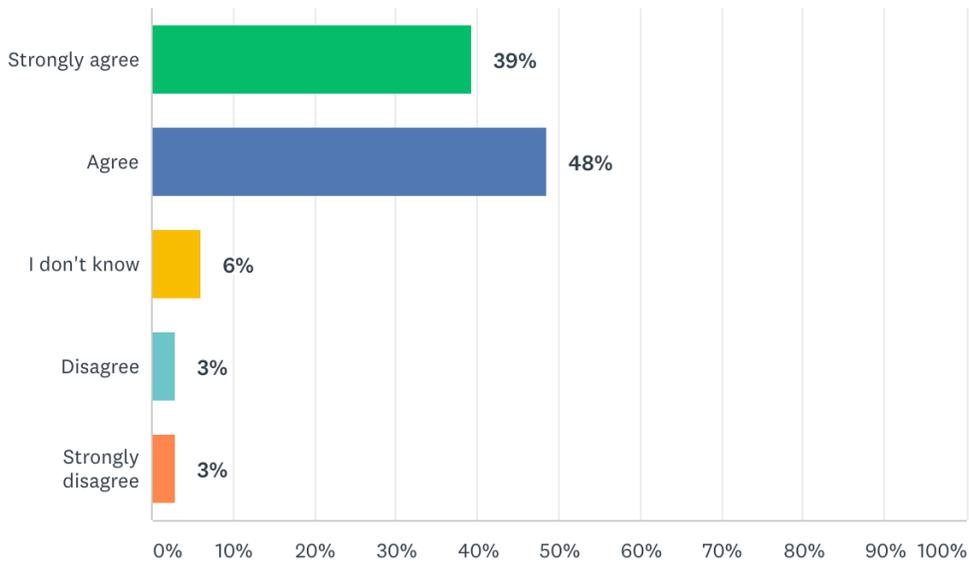
MONITORING. The focus of this survey section was on the extent to which an external entity ensures the organization’s compliance with established policies and procedures related to sexual violence/abuse against individuals with I/DD. When asked if an external authoritative body ensures their organization has **established policies/procedures to reduce the risk** of sexual violence/abuse against residents with I/DD, the majority (87%) of group home providers agreed or strongly agreed that this was the case. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 1.8 with a standard deviation of 0.9.

Figure 60. Percentage of group home providers with external authoritative body that ensures policies/procedures to reduce risk for sexual violence/abuse are established



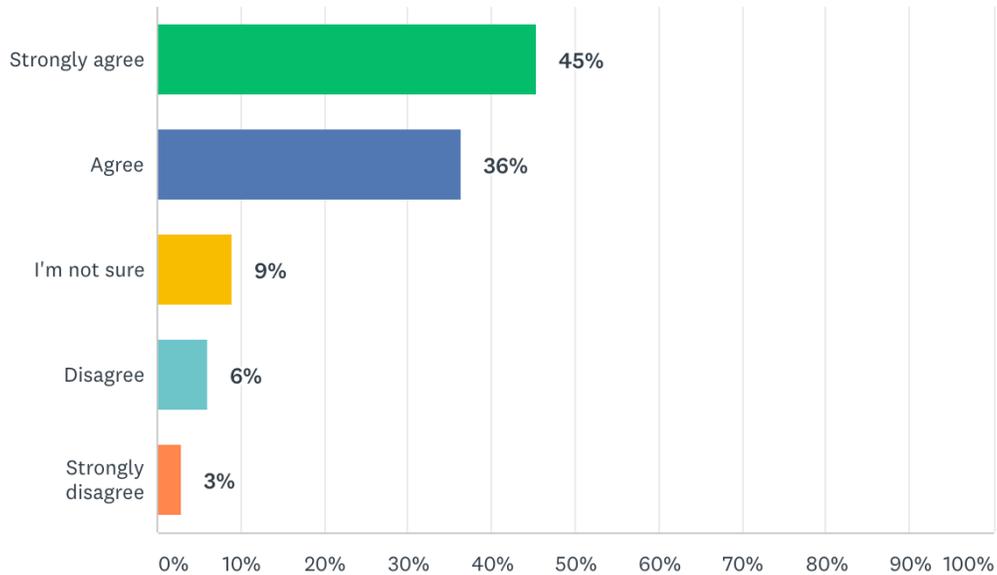
When asked if an external authoritative body verifies that their organization **implements these established policies/procedures**, the majority (87%) of group home providers agreed or strongly agreed that this was the case. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 1.8 with a standard deviation of 0.9. When asked to name this external authority the most frequent response was the Department of Economic Security’s Division for Developmental Disabilities (DDD) and insurance companies.

Figure 61. Percentage of group home providers with external authoritative body that verifies established policies/procedures are implemented



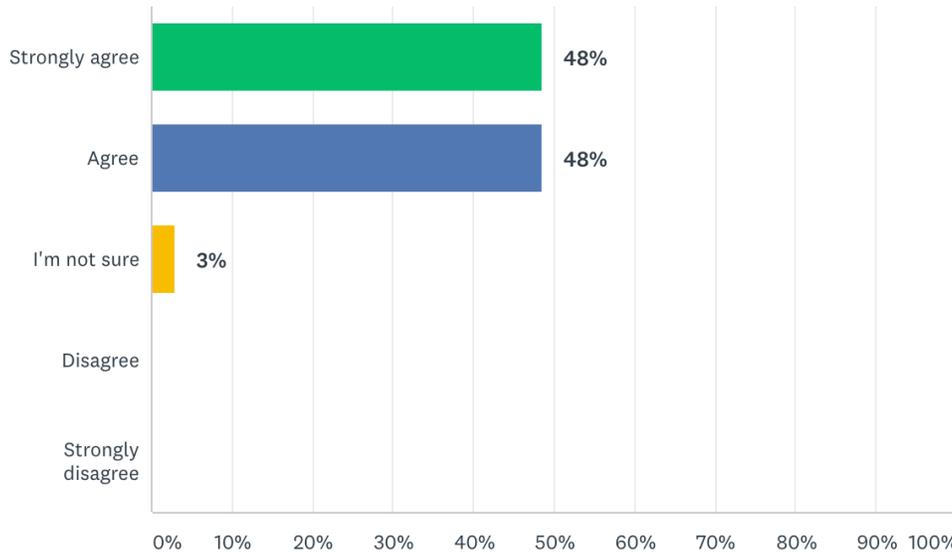
When asked if an external authoritative body is responsible for **following up on what has been done and what is coming next** following a suspected incident, the majority (81%) of group home providers agreed or strongly agreed that this was the case. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 1.8 with a standard deviation of 1.0.

Figure 62. Percentage of group home providers that rely on external authority to follow up and determine what comes next after suspected incident of sexual violence/abuse



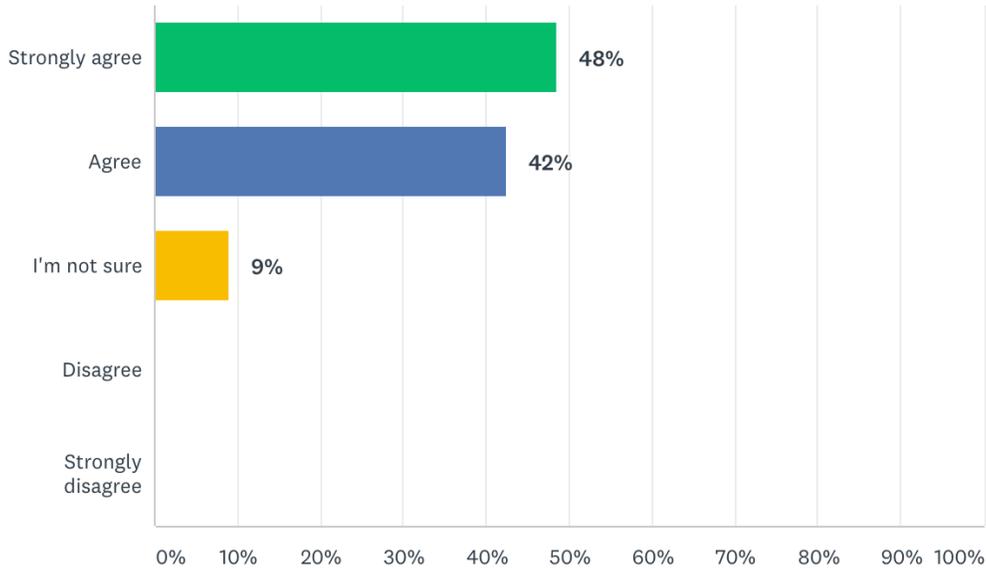
When asked if **residents with I/DD and their families know who to contact** if they believe the organization is being negligent or not following best practices, the vast majority (96%) of group home providers agreed or strongly agreed that this was the case. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 1.5 with a standard deviation of 0.6.

Figure 63. Percentage of group home providers with residents with I/DD and families that know who to contact if they believe their organization is negligent or not following best practices



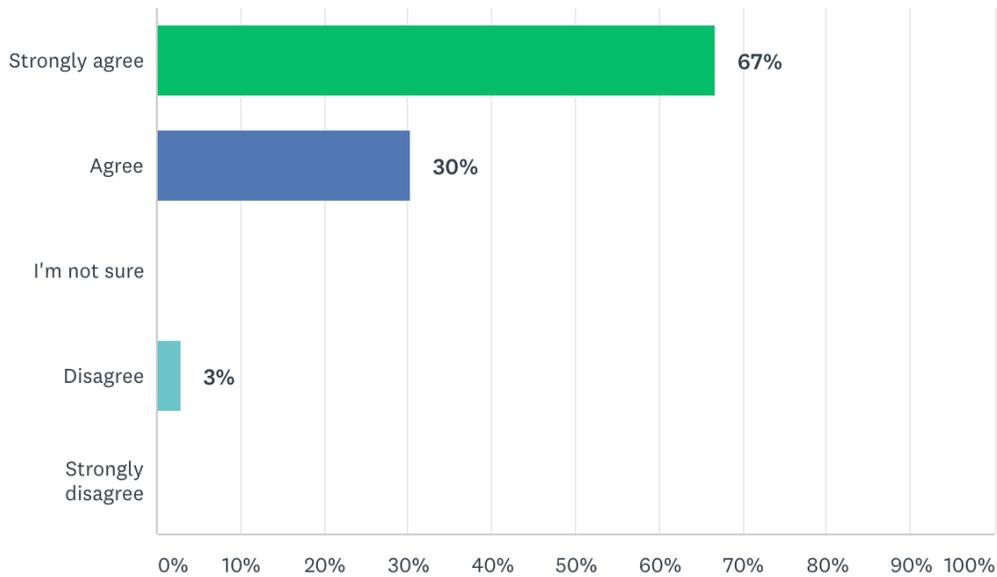
PREVENTION. The focus of this survey section was to determine general prevention efforts and the number of providers using a tiered approach to prevention. The latter was detailed in the *State of the Research* (Kurz et al., 2020) section recommending clearly delineated primary and secondary prevention strategies that differentiate between universal (i.e., all individuals with I/DD and caregivers) and targeted (i.e., high-risk individuals with I/DD and caregivers) strategies. When asked if their organization **actively engages in work to prevent sexual violence/abuse against residents with I/DD**, the vast majority (90%) of group home providers agreed or strongly agreed that this was the case. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 1.6 with a standard deviation of 0.7. When asked to provide specific examples, the most frequent examples included regular trainings (e.g., Article 9), active management, and regular observation. Some notable mentions included same sex assignments (i.e., females staff assigned to female residents), no one-on-one assignments, camera monitoring, and group discussions.

Figure 64. Percentage of group home providers that actively engage in work to prevent sexual violence/abuse against residents with I/DD



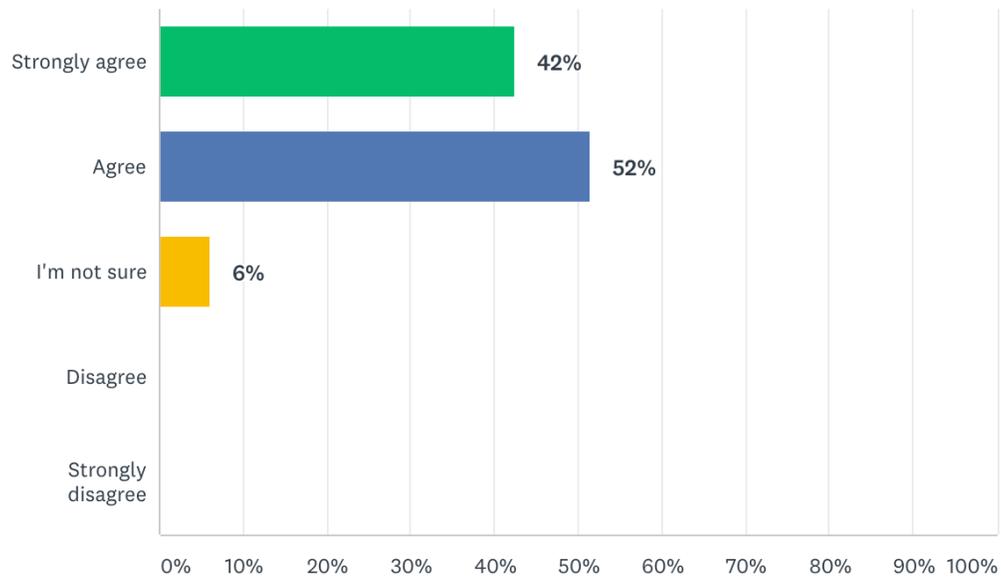
When asked if the **prevention of sexual violence/abuse against residents with I/DD is viewed as a key responsibility**, almost all (97%) group home providers agreed or strongly agreed. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 1.4 with a standard deviation of 0.7.

Figure 65. Percentage of group home providers that views prevention of sexual violence/abuse against residents with I/DD as a key responsibility



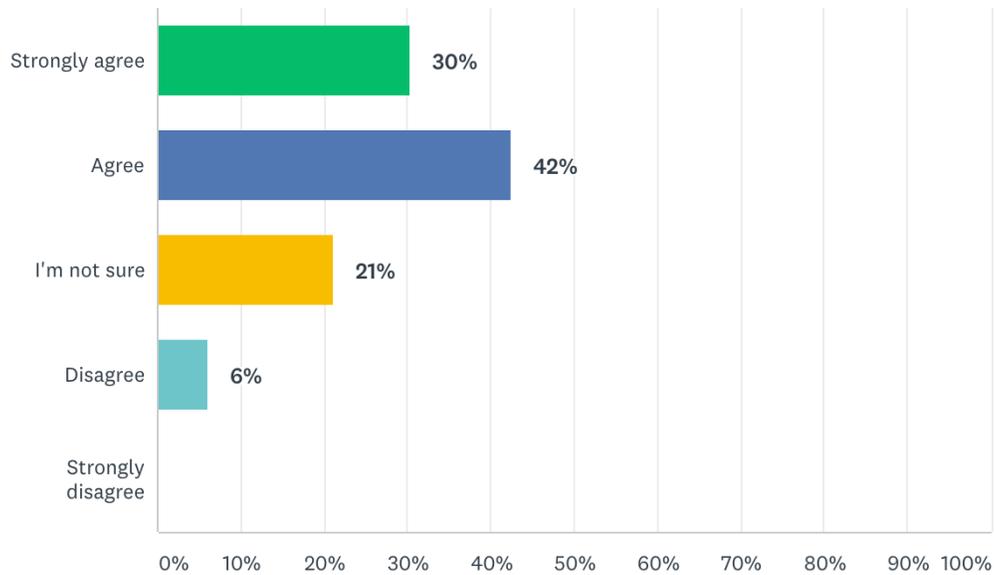
When asked if their organization is **aware of best practices for preventing sexual violence/abuse against residents with I/DD**, almost all (94%) group home providers agreed or strongly agreed. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 1.6 with a standard deviation of 0.6.

Figure 66. Percentage of group home providers aware of best practices for preventing sexual violence/abuse against residents with I/DD



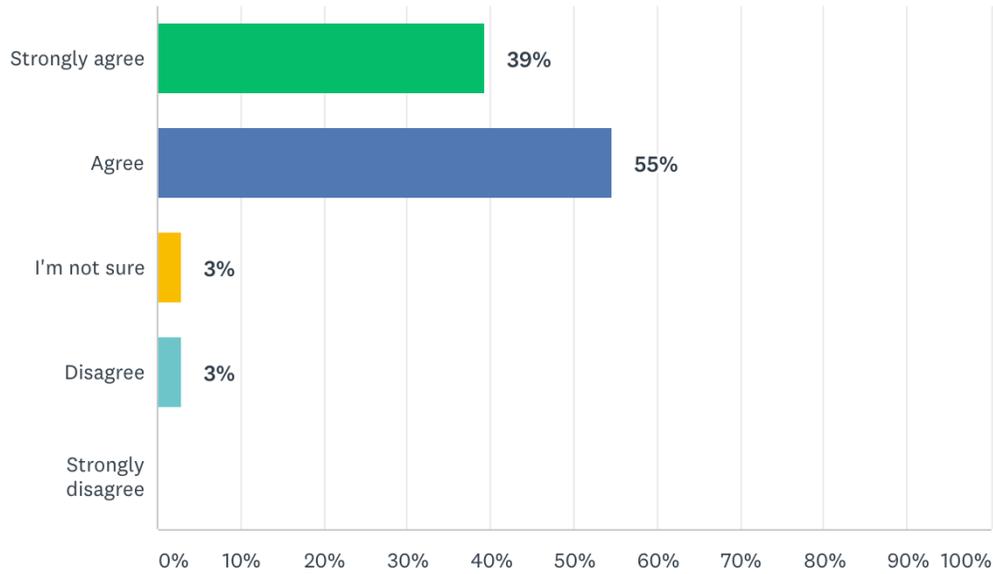
When asked if their organization uses a **tiered approach to prevention** (i.e., universal prevention, targeted prevention for high-risk groups, prevention of re-victimization for individuals with prior experience of sexual violence/abuse), the majority (72%) of group home providers agreed or strongly agreed that such an approach was in place. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 2.0 with a standard deviation of 0.9.

Figure 67. Percentage of group home providers with a tiered approach to sexual violence/abuse against residents with I/DD



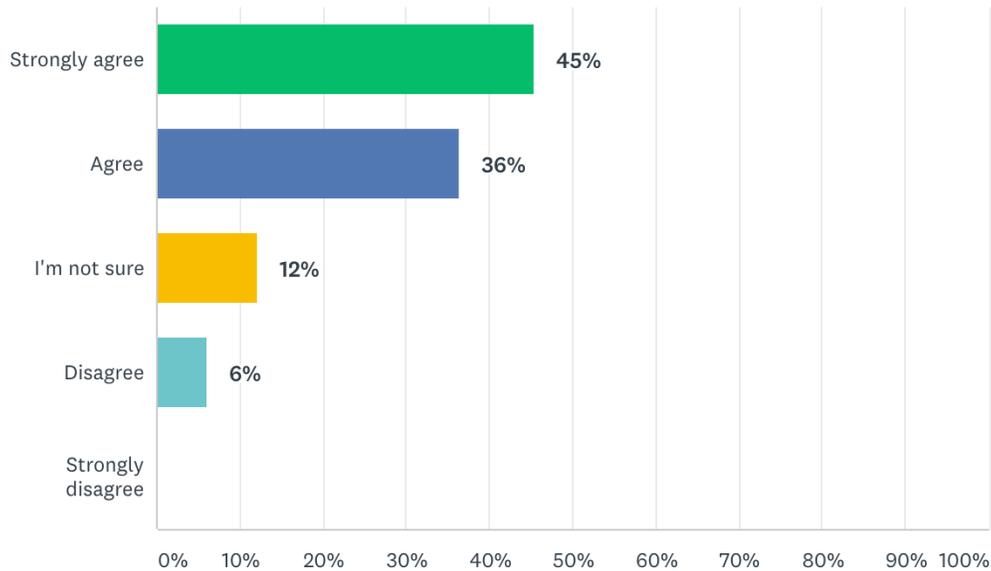
When asked if their organization’s prevention methods include **trainings and policies informed by best practices and empirical data**), the vast majority (94%) of group home providers agreed or strongly agreed that such an approach was in place. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 1.7 with a standard deviation of 0.7.

Figure 68. Percentage of group home providers with trainings and policies informed by best practices and empirical data



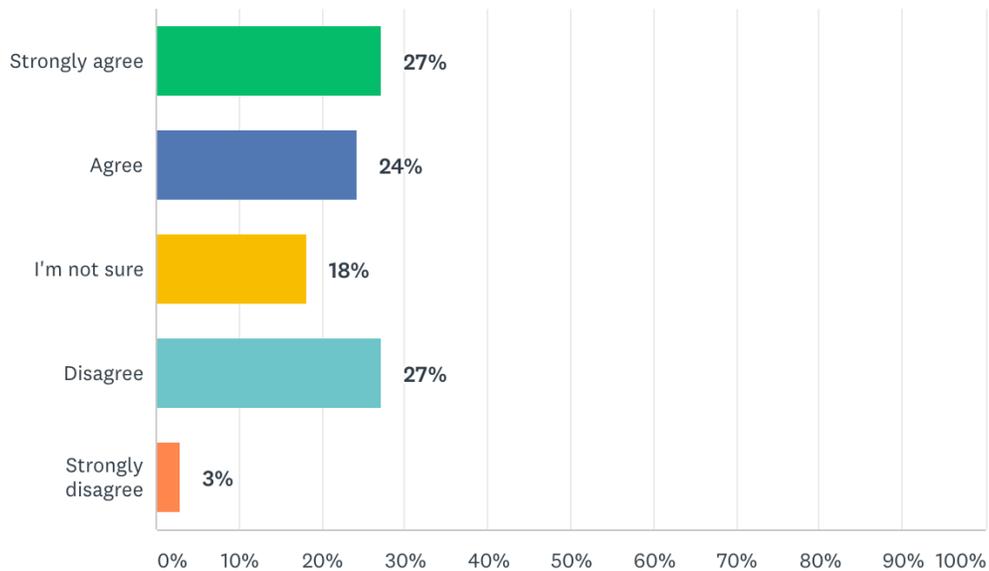
When asked if their organization **trains staff on strategies to prevent sexual violence/abuse** against residents with I/DD, the majority (81%) of group home treatment providers agreed or strongly agreed that they provided such trainings. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 1.8 with a standard deviation of 0.9.

Figure 69. Percentage of group home providers with staff trainings on strategies to prevent sexual violence/abuse against residents with I/DD



When asked if their organization **trains parents/caregivers on strategies to keep their loved ones with I/DD safe** from sexual violence/abuse, half (51%) of group home providers agreed or strongly agreed that they provided such trainings. On a scale from 1 = strongly agree to 5 = strongly disagree, the mean rating was 2.5 with a standard deviation of 1.3.

Figure 70. Percentage of group home providers with parent trainings to keep their loved ones with I/DD safe



LIMITATIONS

The generalizability of the current findings is limited by the response rates of day treatment (33%) and residential group home providers (37%). While both surveys reached about one third of all providers in the state of Arizona, the current sample is likely to represent the most willing respondents for answering questions related to sexual violence/abuse against individuals with I/DD. Given a potential social desirability bias, these willing respondents likely represent the upper ceiling of agreement percentages (i.e., best case scenario). An additional limitation stems from the potentially limited knowledge transfer from owner/administrator to actual staff practice. While an owner/administrator may be very familiar with best practices and confident in their implementation, the same may not apply across all staff members within a given program or facility. We conducted three anonymous spot checks to confirm the presence of key practices and procedures with actual staff members in day treatment programs and group home facilities. Their responses only partially confirmed owner/administrator ratings with key gaps related to trainings (i.e., lack of trainings aside from Article 9) and use of assessment and/or screeners.

KEY FINDINGS

Across all categories, mean ratings and agreement percentages of group home providers consistently exceed those of day treatment providers. This relative high level of self-reported implementation of best practices by group home providers was largely driven by the areas of tracking, monitoring, and prevention as well as related trainings. That being said, there was a considerable amount of consistency among day treatment and group home providers. The two highest rated items for both providers were related to (a) viewing the prevention of sexual violence/abuse against individuals with I/DD as a **key responsibility** and (b) having **internal policies/procedures for staff** on how and when to report sexual violence/abuse against individuals with I/DD. The two lowest rated items for both providers were related to (a) **training parents/caregivers on strategies** for keeping their loved ones with I/DD safe from sexual violence/abuse and (b) **training parents on how and when to report** sexual violence/abuse against individuals with I/DD. As such, this key finding indicates an urgent need to address a **critical training gap for parents** related to both the prevention and reporting of sexual violence/abuse against individuals with I/DD.

Additional findings can be noted based on the lowest ratings for each provider category. For group home providers, the concern for parent trainings extends to **other trainings** for staff on risk assessments and trainings on reporting for residents with I/DD. For day treatment providers, additional concerns are related to reporting. Specifically, **internal reporting policies/procedures** for individuals with I/DD and their parents/caregivers. A summary of the agreement percentage ranges is provided below.

- **Detection**
 - 5 items
 - Day Treatment [44%-87%]
 - Group Home [68%-88%]
 - 3 training-related items
 - Day Treatment [52%-75%]
 - Group Home [60%-75%]
- **Reporting**
 - 3 items
 - Day Treatment [38%-86%]
 - Group Home [50%-100%]
 - 3 training-related items

STATE OF THE PROVIDERS

- Day Treatment [27%-89%]
- Group Home [33%-97%]
- **Tracking**
 - Day Treatment [81%]
 - Group Home [94%-95%]
- **Monitoring**
 - 4 items
 - Day Treatment [61%-85%]
 - Group Home [81%-96%]
- **Prevention**
 - 4 items
 - Day Treatment [42%-88%]
 - Group Home [72%-97%]
 - 3 training-related items
 - Day Treatment [27%-89%]
 - Group Home [33%-97%]

JANUARY 2021

**FAMILIES & CAREGIVERS OF INDIVIDUALS WITH
INTELLECTUAL AND DEVELOPMENTAL DISABILITIES**

LIVED EXPERIENCE

Meghan C. Kenney Velasquez, EdD
Alexander Kurz, PhD
Jenny Mullins
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Focus Groups and Interviews

FAMILIES & CAREGIVERS OF INDIVIDUALS WITH I/DD

LIVED EXPERIENCE

This section summarizes a series of in-depth conversations with families and caregivers of individuals with intellectual and developmental disabilities (I/DD) as well as law enforcement and Family Advocacy Center (FAC) representatives. These semi-structured conversations occurred in the context of over 30 **focus group and cognitive interview sessions** that collectively addressed the lived experience of participants related to the detection, reporting, tracking, monitoring, and prevention of sexual violence/abuse against individuals with I/DD including any training they may have received. As part of a series of research reports (i.e., Kurz, Velasquez, Mullins, & Nicely, 2020; Kurz, Velasquez, Mullins, & Nicely, 2021), this section examines sexual violence/abuse against individuals with I/DD based on a mixed methods research design that collects both quantitative and qualitative data concurrently and then compares the two databases to determine convergence, differences, or some combination thereof. As such, the lived experiences inform the qualitative research strand of this mixed methods study further contextualizing the key findings from the academic research literature and the results from the day treatment and group home provider surveys.

METHODS

The research team conducted **3 focus groups and 31 cognitive interviews** using a semi-structured format that included a combination of introductory rating scales and open-ended questions related to the six categories of interest (i.e., detection, reporting, tracking, monitoring, training, prevention). All interviews were conducted over the phone or video conference to follow safety protocols put in place due to the COVID-19 pandemic. Additional accommodations were made on a case-by-case basis, including access to a licensed therapist during the session, to ensure each individual was able to safely and fully participate in the study.

SAMPLING & RECRUITMENT

To gain a deeper understanding on personal experiences related to each category, the research team used a purposive sampling strategy focusing on the primary caregivers of individuals with I/DD (e.g., family members, relatives, legal guardians but not professional agencies or providers) and individuals with I/DD themselves living in Arizona. Participants were recruited through Facebook groups for families with loved ones with I/DD and personal outreach from research team members using their existing networks in the disability community. Open calls to participate were posted to the Facebook groups twice, while targeted outreach was conducted once. The two recruitment strategies resulted in equal distribution of 30 participants from across the state of Arizona. Broken into subgroups, there were 29 caregivers of individuals with I/DD (referred to as “caregivers” throughout this section of the report) and one individual with I/DD who were interviewed for this research. Participants were compensated for their time with \$25 gift cards.

In addition to the lived experiences of families and caregivers, the research team also sought to gather information from law enforcement and FAC representatives given their instrumental roles pre- and post-incident of sexual violence/abuse against individuals with I/DD. Through direct outreach, the research team recruited six law enforcement officers and 10 FAC representatives from 10 family advocacy centers throughout Arizona. Those 16 individuals participated across three group interviews. This recruitment strategy resulted in a limited convenience sample of law enforcement

officers from two different police departments and a representative sample of FAC representatives from 35% of FACs across the state. In keeping with department and FAC policies, compensation was not offered to law enforcement and FAC participants.

INFORMED CONSENT

All individuals consented to participation through an informed consent process in which written copies of informed consent documents were provided, while also explained to them verbally. In addition to informed consent, all individuals with I/DD and caretakers were offered the option of having a licensed therapist sit in on their interview session for support. As part of informed consent, all 46 participants gave permission for the information they shared anonymously to be included in publication of this report. To honor the informed consent process and protect anonymity for participants, direct quotes are noted but have not been attributed to a specific participant and the majority of information is presented in aggregate form.

ANALYSIS

Interviews were analyzed in two stages, with the contributions from all interviewee populations combined as one sample. In the first stage, the initial set of scaled items, were analyzed quantitatively. For those items, participants were asked to respond using a 1-10 Likert scale wherein the range represented a degree of importance, level of concern, or amount of information depending on the item (specific text of the scaled items is included in the Findings section). Mean scores and ranges were calculated for each item and explanations of ratings were thematically analyzed. The second stage included analyzing the interview narratives using an inductive coding approach that included multiple iterations of open coding, thematic analysis coding, and axial coding. The combination of coding approaches yielded a final **set of 21 codes** representing major themes that were applied to all 33 interviews to discern prevalence of each major theme across the body of interview participants. In the Findings-Qualitative Analysis section the final codes for each research area are listed and an explanation of each code's meaning is explained.

FINDINGS

QUANTITATIVE ANALYSIS

To properly frame each participant's responses, they were asked a set of four questions at the beginning of the conversation. The questions provide a **baseline perspective** of each participant related to the topic of sexual violence/abuse against individuals with I/DD. Specifically, each interview participant from the caregiver, individual with I/DD, and law enforcement subgroups were asked to rate each of the following items on a scale from 1-10, with one representing the extreme low and 10 representing the extreme high end of the importance, concern, and information continuum:

- **How important** is the issue of sexual violence/abuse against individuals with I/DD to you?
- **How concerned** are you that you or your loved one with I/DD will experience sexual violence/abuse? [This item was intentionally omitted from law enforcement interviews]
- **How informed** are you on the issue of sexual violence/abuse against individuals with I/DD?
- **How much information** have state agencies or other service providers provided to you on the topic of sexual violence/abuse against individuals with I/DD?

The results underscored that the issue of sexual violence/abuse against individuals with I/DD was **extremely important** to all respondents (M = 9.9, SD = 0.4). The urgency of this issue for caregivers, however, was striking with all (100%) caregivers expressing being **extremely concerned** (M = 9.1, SD = 1.2) that their loved one will experience sexual violence/abuse. Moreover, the analysis illuminated the level of importance and degree of concern were in stark contrast to their reported level of understanding and amount of information received by state agencies and other service providers. Respondents generally indicated only being **partially informed** on the issue of sexual violence/abuse against individuals with I/DD (M = 6.4, SD = 2.4) with **little to no information** made available to them by state agencies and other service providers (M = 0.8, SD = 0.7).

In addition to each interviewee providing a numerical response to the scaled items, 18 participants also explained their ratings. These explanations were included in the coding process, where **three significant themes** emerged:

1. Informed by personal experience. In general, caregivers who self-reported that they possessed higher levels of information related to sexual violence/abuse against individuals with I/DD had experienced an abuse situation firsthand — through either an incident they or their loved ones had been through. Many reported knowing what to do if they suspected sexual violence/abuse only as a result of *“having gone through it myself,”* often *“fumbling through the process.”*

2. DDD has a communication role to play. Caregivers believe DDD ought to be playing a significant communication role related to the topic of sexual violence/abuse, especially its prevention. One caregiver summed up the sentiment by saying, *“this should be a huge topic that DDD is covering.”* Though this topic was not explicitly asked about, 62% of caregivers who were interviewed brought up this theme.

3. Professional roles inform personal experience. Caregivers who self-reported that they possessed higher levels of information related to sexual violence against individuals with I/DD often obtained the information through job training in their professional roles. In these cases, caregivers universally clarified their rating and explained that the information they had received was related to training in their current or previous employment. Additionally, these caregivers went on to elaborate that they had expected to receive similar or additional information in their role as a parent/caregiver of an individual with I/DD.

QUALITATIVE ANALYSIS

The narrative responses for items beyond explanations of the rating scale yielded 21 major themes, which were extracted from the responses to seven standard questions related to detection, reporting, training, and prevention and two standard questions related to monitoring and tracking. The questions on monitoring and tracking were posed only to FAC representatives and law enforcement officers, as these are wholly institutional functions as defined within the scope of this inquiry and not matters that we would reasonably expect caregivers or individuals with I/DD to be well aware of. Conversely, prevention-focused questions were limited to individuals with I/DD and caretakers due to

the responsive nature of the roles of law enforcement and FAC representatives. **Table 1** summarizes the questions posed within each category.

Table 1. *Initial Interview Questions by Participant Group and Category of Interest*

CATEGORY	OPENING: CAREGIVER AND INDIVIDUALS WITH I/DD	OPENING: LAW ENFORCEMENT
Detection	<p>Do you know what puts you or someone else at risk for being a victim of sexual violence/abuse?</p> <p>Have any of your providers explained to you what they are doing to minimize risk and/or detect sexual violence/abuse?</p>	<p>Do you know what puts you or someone else at risk for being a victim of sexual violence/abuse?</p>
Reporting	<p>Have any of your providers explained to you what their process would be for reporting a suspected incident of sexual violence/abuse?</p>	<p>Do you follow a specific protocol for investigating a suspected incident of sexual violence/abuse? Please explain.</p>
Tracking	N/A	<p>How and what does your department record regarding allegations of sexual violence/abuse and its outcomes?</p>

CATEGORY	OPENING: CAREGIVER AND INDIVIDUALS WITH I/DD	OPENING: LAW ENFORCEMENT
Monitoring	N/A	<p>Are procedures in place for monitoring individuals and/or organizations when an allegation of sexual violence/abuse has been made?</p> <p>If yes, can you tell us more about these procedures? Who does the monitoring? How is it initiated and completed?</p>
Training	<p>Do you know what to do if you or a person you know has experienced sexual violence/abuse?</p> <p>If applicable, how did you know what to do?</p> <p>Have you ever had any sort of training or class about what to do if you or someone you love experiences sexual violence/abuse?</p>	<p>Have you received any specific training on working with individuals with I/DD? Can you tell us more about that training?</p>

CATEGORY	OPENING: CAREGIVER AND INDIVIDUALS WITH I/DD	OPENING: LAW ENFORCEMENT
Prevention	<p>For individuals with I/DD: What can you tell us about how to keep yourself safe?</p> <p>For families/caregivers: What can you tell us about how to keep your loved ones safe from sexual violence/abuse?</p> <p>Who has a role to play in keeping them safe?</p>	N/A

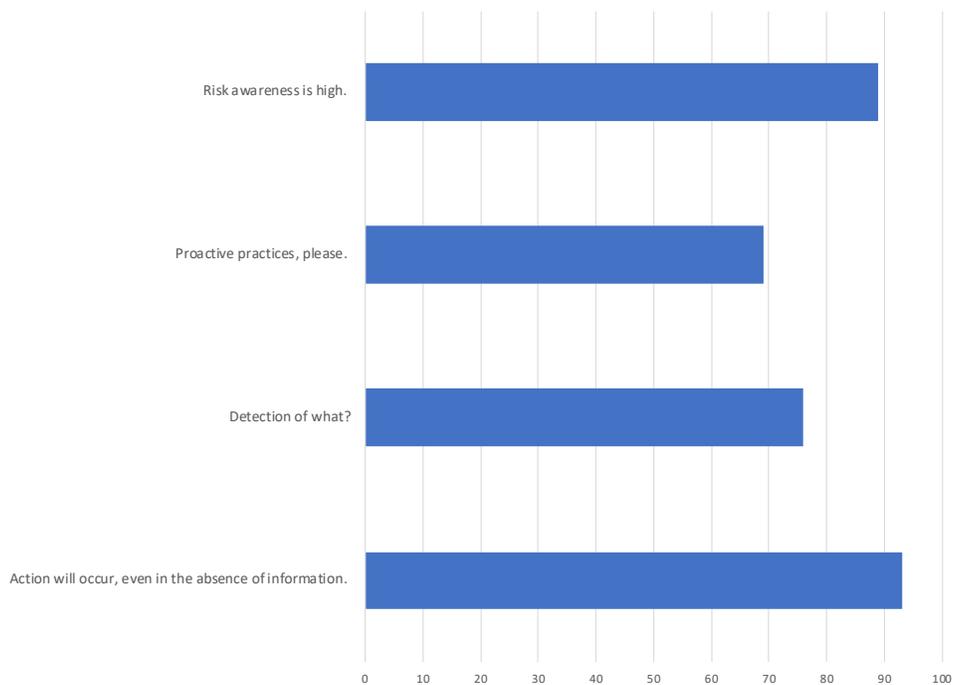
Researchers modified language complexity of opening questions depending on each respondent’s expressive and receptive language abilities. For our purposes, major themes are defined as those present across a substantial subset of interviews and/or those with significant implications according to best practice recommendations found in the *State of the Research*. Once major themes were established, their presence was quantified within the interview population and is reported in Figures 1-6.

In the section that follows, themes are broken out into groups by research area (i.e. reporting, tracking), prevalence is reported, and the theme is explained. The *n* count of many themes have been intentionally excluded to protect interviewee identity. It is also important to note that we have used percentages to report prevalence instead of quantity to account for the variance in applicability to themes within the interview sample. For example, the theme “prevention beyond the early years” is only applicable to interview participants whose loved one has passed adolescence and so the reported prevalence for this theme was calculated using a smaller total than the total participant count. Conversely, any theme not expressly limited by demographic (e.g., age, gender) or contextual characteristic(s) (e.g. service setting, explicit disclosure of having experienced violence) were assumed to apply across all interviewees and thus prevalence was calculated using 46, the total number of interviewees in the sample.

DETECTION. Detection is defined as the action or process of identifying the risk or the presence of sexual violence/abuse against individuals with I/DD. It is a broad category that encompasses assessing an individual’s risk for experiencing sexual violence, practices to proactively identify when instances of sexual violence/abuse have occurred, and practices related to the investigation of allegations of sexual violence/abuse once they have been reported or are suspected. Interviewees from all subgroups (caregivers, individuals with I/DD, law enforcement, and FAC representatives) were asked to provide input on their experiences with detection. Analysis revealed six major themes in this area:

- *Risk awareness is high*
- *Action will occur, even in the absence of information*
- *Detection of what?*
- *Proactive practices, please*

Figure 1. Prevalence of themes for detection



In terms of risk, the conversations confirmed that all participants (i.e., caregivers, individuals, FAC representatives) had a high risk awareness and they unanimously articulated an understanding that individuals with I/DD are at increased risk for experiencing sexual abuse/violence. Interviewees voiced specific factors that compound an individual's risk for experiencing sexual violence/abuse such as communication difficulties, the need for personal hygiene care, susceptibility to manipulation, residing in and/or receiving care in an institutional setting, and mobility limitations. These factors are consistent with those found in the body of peer-reviewed literature.

In addition to the factors noted in the literature with robust empirical support, caregivers also articulated a belief that individuals with aggressive behaviors are more susceptible to experiencing sexual violence/abuse. The foundation for this belief resides in the likelihood for an individual with I/DD who demonstrates aggressive behavior to be restrained and/or to have marks such as bruising on their bodies. Caregivers explained that an aggressor would likely understand that these behaviors are typical of the individual and would provoke them as a means of masking injury that occurred as a result of the abuse. They also expressed that, based on their experiences, people are less likely to believe individuals who demonstrate aggressive behaviors when they report sexual violence/abuse and that perpetrators would intentionally prey on them for this reason. The association articulated by caregivers between aggressive behavior and risk for experiencing sexual violence/assault has received only a cursory review in the academic literature and warrants further study.

Conversely, 83% of the law enforcement officers interviewed expressly said that they **did not know** what put an individual at increased risk for experiencing sexual violence/abuse. Accounting for all subgroups of interviewees, 89% understood that an individual with I/DD is at a significantly greater risk of experiencing sexual violence/abuse.

In addition to risk awareness, the area of detection explored how instances of sexual violence/abuse could be identified and what should be done if an incident is suspected. Sixty-nine percent of caregivers said they wanted service providers and state agencies to use **proactive practices** to detect sexual violence/abuse. This desire is consistent with best practices as articulated in the literature and could include strategies such as administration of screeners or interviewing individuals with I/DD. At present, none of the caregivers or individuals with I/DD cited having ever experienced or been informed about such practices occurring in care settings from which they or their loved one receives services.

When working through questions related to detection, one caregiver asked, “**detection of what?**” They then went on to explain that their daughter had been the victim of sexual trafficking, but that they were unsure if her experience would “count” as a form of sexual violence/abuse. The uncertainty prompted researchers to do an additional review of the interview data to assess the specific nature of the abuse caregivers were referring to in their interviews. This process revealed that interviewees’ conception of sexual violence/abuse may be restricted to rape. It should be noted that due to the sensitive nature of the topic, interviews did not deeply explore individuals’ mental models of sexual violence/abuse, however 76% of caregivers’ descriptions throughout the interviews were limited to descriptions of rape. This could indicate a key gap in understanding and a need for individual and caregiver education on the expansive nature of sexual violence/abuse and the breadth of experiences an individual may encounter.

When asked, “Have any of your providers explained to you what they are doing to minimize risk and/or detect sexual violence/abuse?” 93% of individuals and caretakers said they had not received an explanation. Most of them went on to explain they are “the deterrent” and that the onus of minimizing risk and detecting sexual violence or abuse lies with them. This belief is significant because 93% of caregivers expressing this position also said they would **take action, even in the absence of procedural information**, if they suspected their loved one had experienced sexual violence/abuse. These actions included “mommy investigating,” which consists of asking their loved one about what may have happened and calling a variety of agencies and individuals to solicit input about what to do next. This response poses a tremendous threat to the investigative process and could result in unintended consequences up to and including compromising the ability to pursue a case in court.

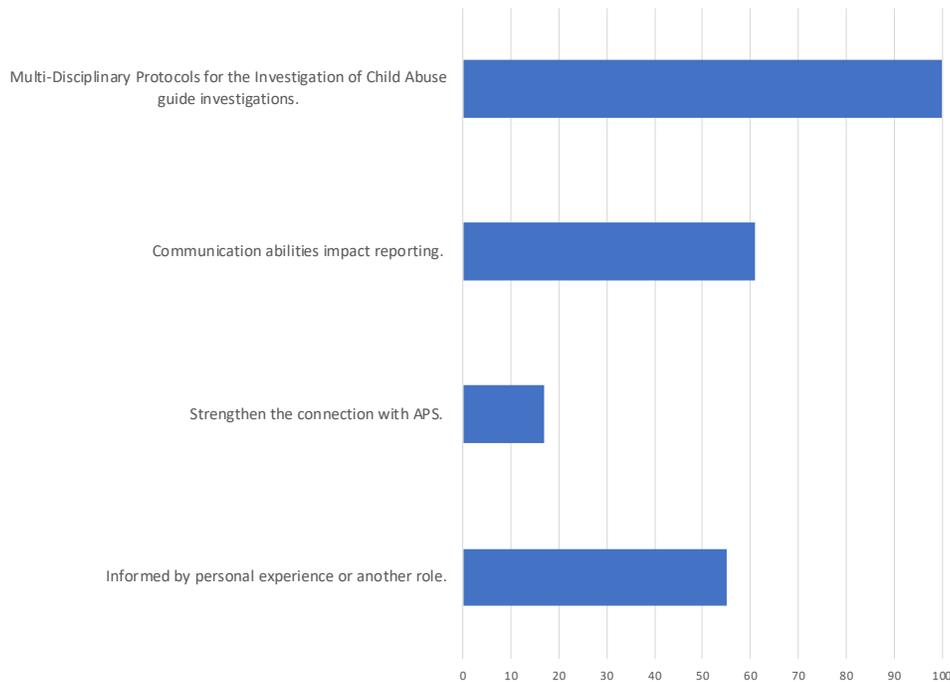
REPORTING. Reporting is defined as the action or process of disclosing an experience of sexual violence/abuse to others and encompasses both self-reporting by individuals with I/DD and reporting on behalf of someone else. Reports can be formally made to law enforcement and other agencies or informally made to caregivers, peers, or others. Reporting is crucial and should be a main focus to ensure that all individuals with I/DD are afforded equal opportunity to safety and justice.

Four major themes were identified in this area:

- *Informed by personal experience or as part of another role*
- *Strengthen the connection with APS*

- *Communication abilities impact reporting*
- *Multi-disciplinary protocols to guide investigations of child abuse*

Figure 2. Prevalence of them for reporting



Caregivers and individuals with I/DD were introduced to the reporting section of the interview by first being asked, “Have any of your providers explained to you what their process would be for reporting a suspected incident of sexual violence/abuse?” Less than 10% of participants said they had been informed of organizational procedures for reporting sexual violence/abuse in their role as a parent, individual with I/DD, or caregiver. It is important to note that this is distinct from reporting procedures a caregiver or individual should follow which were discussed in the detection section of this report.

On the other hand, 55% of caregivers reported they were aware of these procedures and policies but that they had been informed by personal experience or as a part of another role they hold (e.g. as an employee). Within this subgroup of interviewees, 38% disclosed that they had personal experience with sexual violence/abuse. These disclosures were either related to violence/abuse they had experienced or that their loved one with I/DD had experienced. In recounting these situations, interviewees shared that

they now know what to do in terms of reporting because they had “fumbled through it” before. None of these individuals had been directly informed about what they ought to do in terms of reporting nor had they been directly informed as to the process a service provider or organization should follow for reporting an incident of sexual violence/abuse prior to their/their loved one’s victimization. Conversely, caregivers who are also employees of agencies that provide services to individuals with I/DD unanimously talked about receiving formal training on reporting sexual violence/abuse. In these cases, individuals cited Article 9 training, as well as mandatory reporter training, which is discussed in greater detail in the upcoming section on training. This dichotomy represents an opportunity for agencies and organizations to build on work they are already doing with staff training to inform families, individuals, and caregivers.

In the context of organizations and agencies, six interviewees specifically mentioned awareness of the child abuse reporting protocols instituted by Department of Child Safety (DCS). These interviewees, regardless of their loved one’s age, explained that they assumed a procedure would involve calling the DCS hotline and then following the instructions of DCS or law enforcement. Two were uncertain if these procedures would pertain to both children and adults with I/DD and three expressed confusion as to whether there are different reporting processes for male victims and female victims.

Five interviewees, especially those with adult loved ones with I/DD, think the **connection with Adult Protective Services (APS) needs to be strengthened**. Though the perception could not be substantiated or refuted within this scope of work, caregivers believe that law enforcement and service providers do not consistently file reports with APS because they believe there will not be timely or adequate follow up. FAC representatives explicitly said that they follow all mandatory reporting laws and consistently file reports with both DCS and APS when they are involved in sexual violence/abuse cases. Furthermore, caregivers reported confusion about the process for filing a report with APS, who should file reports, and what should happen with a report once it has been filed. Both caregiver and FAC representatives expressed frustration that it is difficult to obtain information on the status of a report once it has been filed with APS.

Law enforcement officers from both departments and FAC representatives said they follow the ***Multi-Disciplinary Protocol for Investigation of Child Abuse*** when they receive a report of sexual violence/assault against an individual with I/DD. They said that this is the same procedure that is followed if the victim is not an individual with I/DD and the same procedure that is followed if the violence/abuse is not sexual in nature. FAC

representatives explained that crafting a specific disability protocol would not only be difficult but that it could create an unintended barrier when a case reaches court. Instead of following unique protocols, the FACs train their staff to work with individuals with disabilities (in some cases, specifically I/DD, in others more generalized training), offer specialized referrals for community services tailored to the unique needs of each individual, engage forensic interviewers with training in working with people with I/DD, and provide “soft rooms and tools for comfort for people with I/DD” when they come into the center.

Within the reporting domain, one of the most striking themes was related to individuals’ **communication abilities impact on reporting**. Over 70% of interviewees expressed a need for individuals with I/DD to have a “safe person” in order to make a report. By “safe,” caregivers described a trust and rapport between the individual with I/DD and the person to talk to as well as some awareness of what to do if a disclosure is made or sexual violence/abuse is suspected. Caregivers, law enforcement, and FAC representatives alike are concerned about unintended interference in investigations if individuals do not know the process to follow when a disclosure has been made or abuse/violence is suspected.

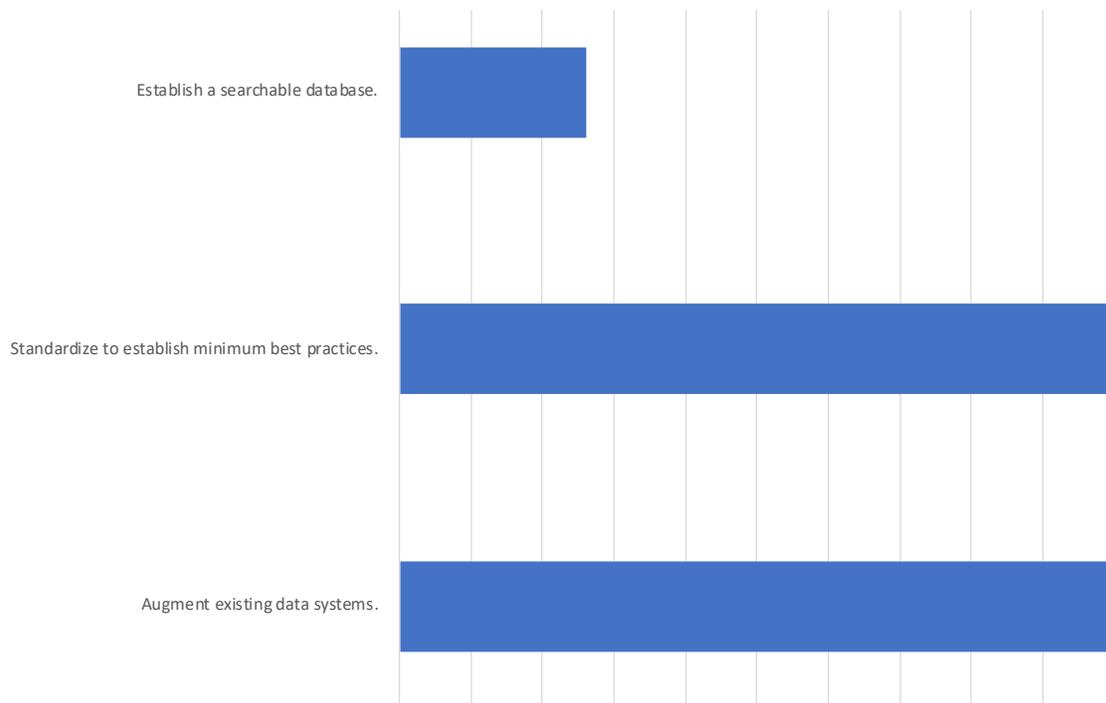
Beyond the procedural, caregivers also raised serious concerns related to reporting and individuals with communication difficulties. Consistent with the literature, this concern was raised in two ways. First, caregivers believe that individuals’ reports of sexual violence/abuse will be immediately dismissed if the victim is unable to provide a thorough verbal account of their experience, including naming the person who perpetrated the sexual violence/abuse. Other caregivers shared that they believe law enforcement and other authoritative agencies (e.g. county attorney and prosecutors) *“don’t think someone with I/DD is capable to make a report so when something happens to them, it gets thrown out.”* Second, communication difficulties can impede an individuals’ ability to make a report at all, especially if they are in need of or dependent upon an assistive communication device (ACD). One mother expressed frustration that was shared by four interviewees around obtaining ACDs for loved ones with I/DD: *“We can’t cut off people’s ways of communicating when we cut the budget,”* she said. Caregivers believe that access to ACDs that are not altered by service providers is crucial to ensuring all people are able to report their experiences and they are concerned that even when an individual has an ACD that service providers can turn off icons or that icons used for naming body parts and expressing violence/abuse are not loaded. Deeper understanding of the process for obtaining and maintaining ACDs is needed and should be explored.

Finally, it is critical to note that none of the interview participants from any subgroup referenced the DD/ALTCS Incident Flowchart or the AHCCCS Incident Flowchart. Due to the submission of these two documents as part of the document request portion of the research projects, interviews were specifically reviewed for mention of these tools.

TRACKING. Tracking is defined as the action or process of recording data on allegations of sexual violence/abuse perpetrated against individuals with I/DD and the associated outcomes. Tracking was an area of the literature that is significantly lacking. Due to the institutional nature of this function, questions related to tracking were only posed to law enforcement and FAC representatives. Themes related to tracking include:

- *Augment existing systems*
- *Standardize to establish minimum best practices*
- *Establish a searchable database*

Figure 3. Prevalence of themes for tracking



In general, themes related to tracking highlight an area of significant opportunity to improve existing systems in Arizona. Law enforcement officers, FAC representatives, and caregivers all expressed a need to bolster tracking systems, although their focus on where and how to do that differed.

Law enforcement officers expressed a need to **augment existing systems** to support adequate tracking of sexual violence/abuse committed against individuals with I/DD. Specifically, all officers expressed a desire for forms used when investigating a report of violence/abuse to be adjusted to include “*check boxes so we can indicate that the case is a sexual assault case,*” and/or that the victim or other individuals involved have I/DD. They explained that doing so would enable software in their respective departments to be easily searched or to find cases for review and flagging for more specialized supports.

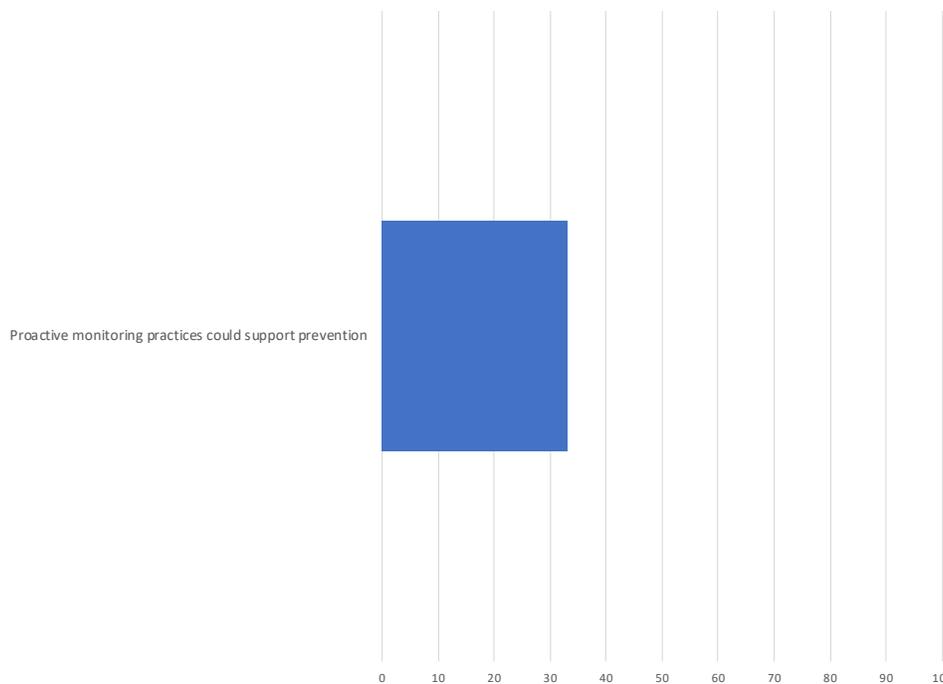
FAC representatives shared a wide variety of tracking procedures and systems specific to each one of their respective centers. There was little to no consistency between accounts of the tools and procedures used to track information from one center to another — other than to ask parents/guardians if the victim has a disability upon intake, but only some centers specify if this disability is I/DD. During the discussion, FAC representatives verbalized surprise at the vast differences in their process and remarked that **standardization of minimum best practices** in this area would be beneficial.

Finally, caregivers raised significant concern related to tracking when they were asked, “What can you tell us about how to keep your loved one safe?” In response to this item, approximately 93% of respondents said something related to carefully vetting providers and anyone who is going to spend time with their loved one. Of those, 26% expressed concern that there is not a central, **searchable database** or website to get information about service providers and service organizations. One caregiver said that “*families are so desperate for help, sometimes they’ll take anyone,*” and she explained the need to have an easy-to-access information point to use when screening a person or agency as a potential service provider. She, along with others, felt there ought to be easier access to information about individuals applying to work in agencies so that caregivers “*don’t have to depend on the memory of someone who has worked here for 30 years*” to know if accusations have been made or complaints have been filed against a particular applicant before. In the absence of such a tracking system, parents are concerned that perpetrators could be moving from one family to another — or from one agency to another — preying on individuals with I/DD.

MONITORING. Monitoring is defined as the action or process of ongoing oversight, typically by an authoritative body, to ensure established policies and procedures are effectively implemented and enforced. It is another area of distinct opportunity for growth based on the information obtained in the interviews. Like tracking, monitoring questions were limited to interviews with law enforcement and FAC representatives, although caregivers also referenced the subject when asked about prevention. One major theme was identified in this area:

- *Proactive monitoring practices could support prevention*

Figure 4. Prevalence of themes for monitoring



One of the prevention practices articulated in the literature is the act of monitoring. Though information was limited, research suggests that **proactive monitoring practices** such as unannounced visits, meetings with parents and residents, published reports on organizations’ performance in monitored areas, and site visits for accountability **could support prevention** of sexual violence against individuals with I/DD. During interviews, 33% of participants talked about a desire for monitoring practices such as these to be implemented where the subject of monitoring would be in residential

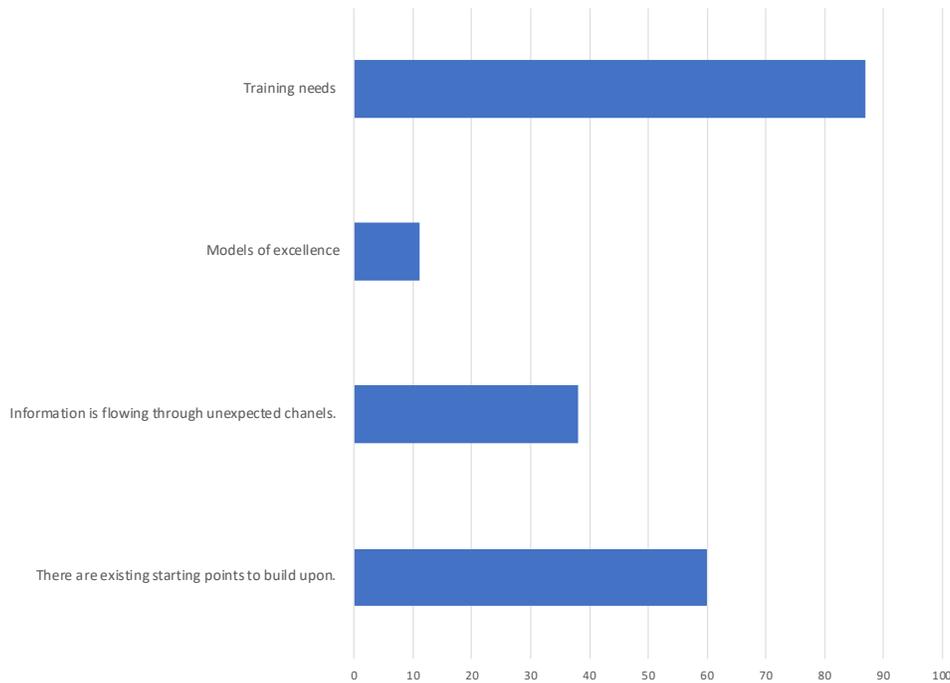
and/or day treatment programs as well as schools and other service providers (e.g., therapists).

FAC representatives and law enforcement did not address monitoring as defined within this scope. Instead, some FAC representatives referenced being monitored by an accrediting body, while law enforcement officers talked about being monitored by body cameras and file review by other officers, and they also mentioned the sex offender registry. While not definitive, this suggests that monitoring as defined for the scope of this inquiry is not currently taking place and is an area for potential improvement.

TRAINING. Training is defined as the action or process of providing individuals with I/DD or those who interact with them the knowledge and skills to prevent, detect, and report sexual violence/abuse against individuals with I/DD. This was one of the richest areas of the literature with over 75 articles meeting inclusion criteria and key themes that included support for providing sexual health education to individuals with I/DD and prevention focused trainings to individuals with I/DD and their caregivers. Structured questions related to training remained broad and asked caregivers if they have “ever had any sort of training or class about what to do if your loved one experiences sexual violence/abuse?” Law enforcement and FAC representatives were asked if they had ever received any specialized training related to working with individuals with I/DD. Four major themes were identified in this area:

- *There are existing starting points to build upon*
- *Information is flowing through unexpected channels*
- *Models of excellence*
- *Training needs*

Figure 5. Prevalence of themes for training



Within the area of training, interviewees commonly referred to two trainings that can serve as **starting points to build upon** in the creation of a more robust suite of training related to the detection, reporting, tracking, monitoring, and prevention of sexual violence/abuse against individuals with I/DD. These starting points are the Article 9 training and mandatory reporter training. These trainings were referenced by interviewees, most often when asked, “Do you know what to do if you or a person you know has experienced sexual violence?” Most interviewees who answered this question by referring to Article 9 or mandatory reporting training were not only caregivers for a loved one with I/DD but also employees of a state agency or service provider. The folks holding dual roles explicitly attributed their training experience to their professional roles and said that they had not received any training in their caregiver roles. Additionally, they also routinely commented on the **inconsistency and insufficiency of Article 9** and mandatory reporter trainings for providers. As one individual said, *“Article 9, it’s just about behaviors. It doesn’t help you keep someone safe unless they are acting out and even then, it’s not keeping them safe from sex crimes.”* When critiquing the limitations of the two trainings, she said, *“mandatory reporting, well, you have to already have something to report”* when critiquing the limitations of the two trainings. Two interviewees specifically

recommended that Article 9 training be adapted for parents because *“the information is valuable. There are lots of behaviors, and parents need this kind of information.”* However, another interviewee clarified, *“parents who get Article 9 think it is stupid. It has to be changed to be specifically for them to make a difference.”*

Aside from Article 9 and mandatory reporter training, caregivers also referred to trainings being provided by Raising Special Kids, DCS, DDD, and UCLA. Caregivers unanimously reported that Raising Special Kids’ and UCLA’s trainings were **models of excellence**. Similarly, though not described in as great of detail, trainings offered by University of Arizona and Autism Society of Greater Phoenix related to personal safety were touted as *“filling the gap of information.”* Our team did not have access to these training materials to assess their content compared to research-based best practices, however caregivers reported that the trainings were thorough, easy to understand, and designed with individuals with I/DD in mind. Fewer caregivers pointed to DCS and DDD as origin points for training (n=3), but those who did specifically said that the DCS sponsored training offered post incident (the interviewee could not remember the specific name of the training.) and the DDD ‘Stranger Danger’ trainings were *“very helpful.”*

The last theme, related to current practices in training, emerged as caregivers explained how they found out what to do in terms of preventing sexual violence/abuse against their loved ones with I/DD. Analysis revealed that much of this **information is flowing through unexpected channels**. Specifically, caregivers reported that pediatricians and therapists have been *“the most helpful people”* in learning how to keep loved ones with I/DD safe. Even though none of the interview participants were asked about the contributions of these service providers specifically, 28% mentioned their support and the high-quality information they have provided. At the same time, caregivers of adults with I/DD who talked about contributions of these service providers also unanimously expressed concern about the decrease in services, availability of information, and support when their loved one transitioned from childhood to adulthood. One mother said, *“after he turned 18, there was nothing,”* when explaining the drastic change in services and support.

Exploration of training revealed several **training needs** for a variety of audiences. First, caregivers expressed a desire for readily available sexual health training for their loved ones with I/DD. Consistent with the literature, caregivers want a training that is developmentally appropriate and more comprehensive than abstinence-based trainings.

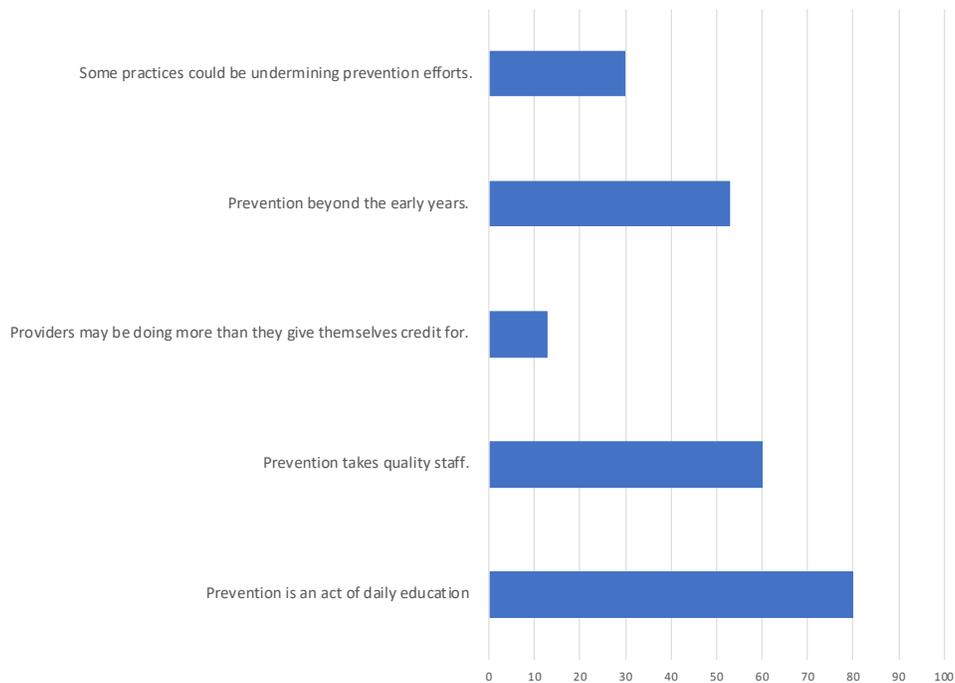
Second, caregivers and FAC representatives expressed a need for prevention and detection-focused trainings geared specifically toward caregivers. These trainings should follow best practices found in the literature and respond to caregiver desires for training materials to be easily referenced, training to include information on locally available services, to be expansive in addressing the gamut of sexual violence/abuse that their loved ones could be subjected to (i.e. sex trafficking, inappropriate touching), as well as what to do and what not to do if they suspect their loved one has been the victim of a sexual assault. Third, law enforcement needs more training on working with individuals with disabilities, specifically I/DD. Current trainings for law enforcement come from a variety of training agencies and individuals resulting in inconsistent experiences and knowledge for trainees. All training, regardless of the audience (caregiver, individual with I/DD, FAC, law enforcement) should follow best practices found in the literature including refreshing training on a regular basis. Further, caregivers expressed a desire for DDD to be vetting these trainings for quality and serving as a primary point of communication about them when they become available.

PREVENTION. Prevention is defined as the action or process of stopping sexual violence/abuse against individuals with I/DD before it occurs and is of utmost concern to safeguard individuals with I/DD. Interview questions on prevention were limited to interviews with individuals with I/DD and caregivers. Due to the responsive nature of FACs and law enforcement, prevention practices as defined in the literature likely fall outside of their respective scopes of work. With caregivers on the other hand, prevention was a top-of-mind topic as 93% of caregiver participants rated their level of concern that their loved one would experience sexual violence/abuse an 8-10, or “extremely concerned.” Many caregivers went on to qualify their rating, expressing that their concern has been long-lasting, “*even before Hacienda,*” the well-known case in which a woman with I/DD residing in a group home was sexually assaulted while under the group home’s care. Another caregiver explained, “*Just being her puts her at risk. Having a disability puts you at risk. I want to know how to keep her safe and what other people who should be keeping her safe can do, too.*” Alongside an acute risk awareness, questions related to prevention surfaced several themes in caregiver and individual interviews. They include:

- *Prevention is an act of daily education*
- *Prevention takes quality staff*
- *Providers may be doing more than they give themselves credit for*

- *Prevention beyond the early years*
- *Some practices could be undermining prevention efforts*

Figure 6. Prevalence of these for prevention



One of the most striking themes that appeared during interviews was that **prevention is an act of daily education**. Caregivers unanimously reported that keeping their loved ones safe from sexual violence/abuse is an ongoing effort, primarily rooted in communication, practice, general awareness of their right to be safe, awareness of and boundaries for their bodies, and what constitutes an inappropriate action or behavior. Caregivers reported using a variety of tools and techniques to do this including explicitly teaching their loved ones the anatomically correct names for body parts and consistently using that language, reading books about boundaries, body awareness, and safety, practicing and praising/rewarding desired behaviors that support safety (e.g. coming from the shower with a towel on), and establishing strict rules against *“keeping secrets.”*

To these ends, caregivers reported that doing **this daily education would be greatly supported if there were more tools at their disposal**. Specifically, caregivers articulated a need for a variety of reading materials (e.g., books, posters, pamphlets) that

are written in plain, accessible language at a developmentally appropriate level covering topics such as body boundaries, grooming behaviors, “tricky people,” and what to do if you or someone you know experiences sexual violence/abuse. Additionally, caregivers reported needing more materials designed with them in mind. One mother said, “*we need more. More for us on things like grooming and sex trafficking*” while another explained her need to access materials that address prevention for teenage and adult individuals with I/DD. Finally, specific training and education materials that support caregivers in working with their loved ones to develop a sense of self identity and self worth. “*We spend a lot of time making [individuals with I/DD] fit in,*” said one caregiver, “*and not enough time on who they are and helping them to develop a sense of self.*”

Related to prevention being an act of daily education, caregivers of children with I/DD articulated greater confidence in their understanding of how to help keep their loved ones safe than did their counterparts with teenage and adult loved ones with I/DD. One caregiver described her experience with prevention related to her teenage loved one as “*walking in the dark*” as she and others expressed the lack of information related to **prevention beyond the early years**. Specifically, balancing their loved ones’ need for autonomy and relationships with direct supervision — the most commonly cited method of parental prevention (90%) — is a point of tension. “*We’ve been extremely protective. We are not comfortable with her doing normal things like going to the movies. Honestly, we’ve stifled her growth,*” said one caregiver as she lamented the struggle with safety as their loved one “*grows up.*” “*Ages 0-17, I knew what to do,*” but now, with “*apps and social activities, I need more information. I don’t know as much as I should.*”

In the absence of providing direct supervision and daily education, caregivers often rely on **quality staff** to help keep their loved ones safe. Caregivers frequently (28%) described long, arduous processes to find, interview, and vet providers that they felt they could trust with “*direct access*” to their loved ones. These processes are made immeasurably more challenging without a centralized information source to verify qualifications and to confirm the absence of allegations/investigations/convictions of abuse. Additionally, many caregivers expressed empathy for service organizations such as day treatment programs and residential group homes because they believe “*it’s so hard to find good staff and keep staff when the pay is so low.*”

In addition to making efforts to hire and retain quality staff, **providers may be doing more than they give themselves credit for** when it comes to prevention of sexual violence/abuse. While the mean score for caregivers’ ratings when asked, “How much information have state agencies or other service providers provided to you on the topic

of sexual violence/abuse against individuals with I/DD?”, was one, or “none,” caregivers went on to cite specific examples of what various service providers do for the sake of prevention. For example, one caregiver shared that she appreciates that the program her loved one is enrolled in implements a *“two-person protocol”* and the use of one-way mirrors as means to limit opportunity for sexual violence/abuse to occur but also said that they have not shared any information with her related to sexual violence/abuse. Similarly, another caregiver described *“checks and balances”* being implemented in the program his loved one attends, but also said *“zero information”* has been shared with him related to sexual violence/abuse and its prevention. These contrasting points of view illustrate the possibility that providers may be doing more to keep individuals with I/DD safe than caregivers realize. In the cases that surfaced through interviews, providers not specifically saying the intent of certain practices is to reduce risk for and/or to prevent sexual violence/abuse leaves room for under awareness of the best practices that are in place.

Finally, it is important to note there is a significant concern that **some practices could be undermining prevention efforts**. Congruent with findings in the literature, two caregivers explained, *“the challenge is we put our hands on children with disabilities more than neurotypical kids.”* Some therapies and practices *“teach people with I/DD to comply. [Teaching compliance without also teaching boundaries, safety and a sense of self,] is extremely dangerous. It makes people with I/DD more vulnerable to sexual violence/abuse.”* Especially given the widespread use of therapies focused on contingencies and positive reinforcement (of compliance) and the need to engage in physical contact to provide adequate care to many individuals with I/DD this area of concern warrants additional research; especially a study on how to effectively mitigate unintended consequences while not diminishing the quality or impact of successful therapies.

LIMITATIONS

The design of this portion of the research study posed a number of strengths and limitations. Strengths included the ability to obtain firsthand accounts of lived experience by a large sample of caregivers of individuals with I/DD and the ability to deeply explore key concepts with caregivers, law enforcement officers and FAC representatives.

Limitations of this analysis include a small sample size of law enforcement officers and individuals with I/DD, the sensitive nature of the subject matter, and potential reflexivity of the researchers. The limited sample size of law enforcement officers has

significant implications for the generalizability of the findings. The work of this study has demonstrated the variability in practices from one police department to another and thus findings cannot be assumed to hold true for agencies outside of those included in this study. Limited engagement with individuals with I/DD restricts study findings to the accounts of caregivers or secondhand experiences and testimonies on behalf of individuals with I/DD. These individuals are capable of representing their own experiences and further work should be done to understand their lived experiences directly. Finally, a phenomenon known as reflexivity (Brannick & Coghlan, 2007; Rubin, 2012) has the potential to impact any qualitative study as the experiences and viewpoints of the researcher cannot be fully extracted from the analysis process. To limit these effects, researchers adhered to best practice, worked in teams, and maintained relative objectivity to the fullest extent possible.

SUMMARY AND KEY FINDINGS

In summary, the research team conducted interviews with 29 caregivers, one individual with I/DD, six law enforcement officers, and 10 family advocacy center representatives, amassing nearly 50 hours of interview data. Those data were analyzed to uncover key themes that impacted a substantial number of interviewees and/or that were significant according to best practices found in the peer reviewed literature (see *State of the Research*). Using this approach, a total of 21 themes were identified across six research areas. The themes and research areas are summarized in **Table 2**.

Table 2. *Summary of Key Themes by Research Area*

CATEGORY	KEY THEMES & PREVALENCE PERCENTAGES
Detection	<ul style="list-style-type: none"> • Risk awareness is high (89%-100%) • Proactive practices, please (69"%) • Detection of what? (76%) • Action will occur, even in the absence of information (93%)
Reporting	<ul style="list-style-type: none"> • Multi-disciplinary protocols for the investigation of child abuse guide investigations (100%) • Communication abilities impact reporting (61%) • Strengthen the connection with APS (17%) • Informed by personal experience or another role (55%)
Tracking	<ul style="list-style-type: none"> • Establish a searchable database (26%) • Standardize to establish minimum best practice (100%) • Augment existing data systems (100%)
Monitoring	<ul style="list-style-type: none"> • Proactive monitoring practices could support prevention (33%)
Training	<ul style="list-style-type: none"> • There are existing starting points to build upon (60%) • Information is flowing through unexpected channels (38%) • Models of excellence (11%) • Training needs (87%)
Prevention	<ul style="list-style-type: none"> • Some practices could be undermine prevention efforts (30%) • Prevention beyond the early years (53%) • Providers may be doing more than they give themselves credit fo (13%) • Prevention takes quality staff (60%) • Prevention is an act of daily education (80%)



KEY FINDINGS

Using the aforementioned themes, analysis revealed a suite of **key findings** that should be considered when assessing the state of the system as it pertains to detecting, reporting, monitoring, tracking, training, and ultimately preventing sexual violence/abuse against individuals with I/DD.

- ✓ Caregivers believe DDD should be a primary source of information on the topic of sexual violence/abuse against individuals with I/DD and would welcome increased communication [1]
- ✓ Caregivers are aware of the risk factors associated with an individual with I/DD experiencing sexual violence/abuse. Other stakeholders such as law enforcement, are not as well versed in these risk factors and would benefit from additional training [2]
- ✓ Detection of sexual violence/abuse may be limited by mental models of what constitutes sexual violence/abuse. Most individuals seem to limit this understanding to rape, which is not sufficiently inclusive of what an individual with I/DD may be subjected to (i.e., sex trafficking, pornography) [3]
- ✓ Caregivers would welcome the use of proactive practices to detect sexual violence/abuse. These could include universal and targeted screeners for those at the highest risk [4]
- ✓ Caregivers are self-reporting that they will take action, even in the absence of procedural information should they believe their loved one has experienced sexual violence/abuse. This is a key system gap as these actions could negatively impact investigation of sexual violence/abuse cases [5]
- ✓ Many caregivers and individuals become aware of what to do if they suspect an individual with I/DD has been the victim of sexual violence/abuse by experiencing trauma themselves or by receiving training in their place of work [6]
- ✓ Proactive monitoring of residential, day treatment, and other service providers appears to be very rare at this time [7]
- ✓ Article 9 and mandatory reporter trainings are taking place, although inconsistently [8]

- ✓ Local non-profit agencies and universities have produced excellent trainings geared toward caregivers of loved ones with I/DD. If more training is produced, these could be considered local models of excellence [9]
- ✓ Sexual health training for individuals with I/DD and prevention and detection training for caregivers of loved ones with I/DD are needed. None of the caregivers or individuals with I/DD who participated in interviews reported having experienced any of these types of training [10]
- ✓ Pediatricians and therapists are providing a great deal of information and informal training to caregivers [11]
- ✓ Caregivers are gravely concerned about the lack of information and decrease in services once their loved one turns 18 years old [12]
- ✓ Training is a key gap in the current system. Existing training is geared toward employees of state agencies and/or service providers, not caregivers or individuals with I/DD [13]
- ✓ Caregivers are aware of foundational best practices in prevention (i.e., teaching their loved ones anatomically correct names for body parts, rehearsing what to do in specific situations), but would greatly benefit from additional materials such as books and trainings to build their own knowledge and support them in educating their loved ones. This is especially true when it comes to addressing sexual health and intimate relationships [14]
- ✓ Navigating prevention of sexual violence/abuse against individuals with I/DD is much more challenging for caregivers after loved ones enter their teenage years. Balancing loved ones' needs for autonomy and independence with direct supervision (the most frequently name strategy for prevention by caregivers) becomes more difficult as the desire for social interactions and personal relationships grows with age. Additionally, resources geared toward an older audience such as books and videos, are more limited [15]
- ✓ Providers may be doing more to prevent sexual violence/abuse than their members and members' caregivers have been made aware of. A limited number of caregivers reported specific practices that some day treatment programs and residential group homes have put into place that align with best practices found in the literature (e.g., two-person protocols for personal hygiene care) [16]

LIVED EXPERIENCE

- ✓ Prevention in institutional and organizational settings requires high quality staff which are difficult to recruit and retain. Low pay may be a significant barrier to employee recruitment and retention in this area [17]
- ✓ Some common practices focused on positive reinforcement for compliance could be add odds with efforts to prevent sexual violence/abuse by desensitizing individuals with I/DD to other people touching them and by building a culture of compliance in organizations/institutions and even homes where individuals with I/DD reside and receive therapies [18]