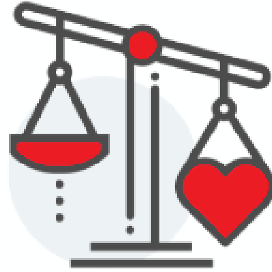

# Sexual Assault Prevention and Response for People with IDD: A Gap Analysis Framework

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October 2021

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This project is supported by the Texas Council for Developmental Disabilities (TCDD) through a grant from the U.S. Administration for Community Living (ACL), Department of Health and Human Services, Washington, D.C., 20201. Grant number available by request. Grantees receiving government sponsorship are encouraged to express their findings and conclusions. Opinions do not necessarily represent official TCDD or ACL policy.

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# Executive Summary

People with IDD (PwIDD) are one of the most at-risk groups for sexual assault in the United States. Their risk is exacerbated both by aspects of their disabilities, such as communication challenges and reliance on others for daily living help, and by interpersonal and systemic biases that discount them as vital, productive members of the community and render them invisible. In fact, these stressors are so powerful and so entrenched that they impact every aspect of the sexual assault continuum, from awareness and prevention through reporting, adjudication, and recovery. These stressors also reinforce themselves and each other—confounding the identification and implementation of solutions able to make a significant impact on this epidemic.

Research and practice have identified individual components (beliefs, approaches, programs, tools) along the continuum that contribute to or alleviate these stressors in specific contexts. However, a true and clear picture of the depth and breadth of the epidemic of sexual assault against PwIDD that organizes, describes the relationships between, and prioritizes action around these stressors has not been presented. This framework seeks to fill this gap, identifying challenges along the sexual assault prevention and response continuum that reinforce or worsen outcomes and opportunities that show promise in remedying them.

The framework consists of seven domains, each focusing on a specific aspect on the continuum of sexual assault of PwIDD. These domains are:

- **Risk Factors:** The multiple and intertwined factors that increase the risk of sexual assault, including personal factors, disability-related factors, and systemic/institutional factors and the importance of learning about and recognizing these risk factors throughout the sexual assault continuum
- **Awareness**: The knowledge that PwIDD experience sexual assault at much higher rates than the general population, that their experience and needed supports are different from those for people without disabilities (though no less valid, effective, and necessary), and that awareness of these issues is paramount to effecting positive change
- **Prevention**: the factors that can empower PwIDD with knowledge and skills to keep themselves safe and, more importantly, to task the people, organizations, and agencies that live and work with them to create and promote environments in which sexual assault is visible, intolerable, and met with swift action
- **Reporting**: the factors that inhibit self-reporting of sexual assault by PwIDD, the lack of capacity to effectively investigate these crimes, and the dangerous situation that occurs when voluntary or mandatory reporting meets investigatory inaction and survivors are left unprotected
- **First Response**: the attitudinal shifts and specific tools and strategies needed by first response professionals to effectively document assault and ensure the safety and well-being of the survivor as they begin their adjudication and recovery processes
- **Adjudication**: the attitudinal shifts and specific tools and strategies needed in the criminal justice agencies to successfully prosecute cases of sexual assault against PwIDD and how they may be different than for people without disabilities

- **Survivor Support**: the factors that advance or inhibit development and use of appropriate supports for survivors of sexual assault with IDD and why these supports are vital for recovery

The framework also includes two sections titled *Special Populations* and *Special Issues*. In our research, we found that some populations of PwIDD, such as those from marginalized groups, of a specific age, or who communicate without speech are impacted differently from others across the entire sexual assault prevention and response continuum. Similarly, some issues such as congregate housing and reliance on the perpetrator span the continuum. These are summarized and expanded on in each section.

Finally, PwIDD are often left silent in research and practice on issues impacting their lives. Nowhere is this, or its dangerous effects, clearer than in work related to sexual assault prevention and response. Silence perpetuates the epidemic. It diminishes PwIDD's power to protect and heal themselves, and it absolves others from responsibility or action. To ensure that PwIDD have a voice that is central and critical to our work, we engaged in a participatory research process in which a self-advocate survivor was a key and equal member of the research team. Their experiences, opinions, and beliefs are included at point-of-relevance throughout the framework. In addition, we convened a series of listening sessions with self-advocates and other stakeholders to further explore their understanding of the sexual assault prevention and response continuum. Their perspectives are also featured throughout the framework.

## Key Findings and Recommendations

### *Risk Factors*

People with disabilities are at a significantly higher risk for experiencing sexual assault than those without disabilities, and this risk is compounded by many factors related to disability, identity, and other life factors. Risk factors simultaneously increase a person's risk of being assaulted and decrease the likelihood the assault will be reported and successfully adjudicated, and that the survivor will receive needed recovery support. Thus, awareness of risk factors and attention to them in remediation strategies across the sexual assault prevention and response continuum is critical.

Actions:

- Anyone supporting or working with PwIDD should educate themselves about these risk factors as a baseline strategy to reduce risk wherever possible, including the often complex ways factors interrelate and reinforce each other.
- Congregate living facilities should audit their policies and procedures with respect to their contribution to risk, including safety planning, resident education, staffing policies, and reporting procedures.
- Attention must be paid across the sexual assault prevention and response continuum to the intersection of PwIDD's desire for relationship, their varying levels of understanding boundaries, and the fact that perpetrators are typically known and in close proximity to survivors. This intersection creates dangerous situations where PwIDD may become victim or perpetrator and where doubt about a survivor's account based on bias may diminish a survivor's chance for justice and thus recovery.

- Sexuality and relationship education programs, in particular, must not shy away from addressing these sensitive and vague topics and must take care to avoid oversimplifying their complexities.
- Criminal justice agencies personnel responsible for investigating and adjudicating these crimes must do so with an understanding of these complexities and avoid making assumptions that might result in poor adjudication outcomes.

### *Awareness*

The epidemic of sexual assault against PwIDD occurs largely in darkness and silence. A mandatory first step to effectively combating it is to bring these issues—however painful and uncomfortable—into our societal consciousness. All stakeholders need to confront their own biases and learn to recognize the signs that a PwIDD has been assaulted.

**Actions**

- Those in a position to see PwIDD on a regular basis, such as family, friends, allies, and service providers, should receive detailed, specific training on recognizing the signs that a sexual assault has occurred and what to do next. This training should be free or at low cost and easily accessible to all wherever and whenever it is needed.
- Anti-bias training across the sexual assault continuum should focus on debunking myths about PwIDD and their sexuality, address intersectional biases, incorporate the voices of PwIDD, and emphasize a person-centered approach.

### *Prevention*

Research demonstrates the best tool to prevent sexual assault of PwIDD is appropriate sexuality and relationship education. Unfortunately, many PwIDD never receive this education, or if they do, it is inappropriately oversimplified, inaccessible, or incomplete. When PwIDD are left to learn on their own, they often turn to peers or the internet. This opportunity for miseducation leaves them vulnerable to sexual assault—either as the victim or the unintentional perpetrator. Education on many fronts is needed. PwIDD require better education on relationships and sexuality. Families, friends, allies, and service providers need to understand and accept the reality of PwIDD as sexual beings and educate themselves on the strategies and tools they can use to promote healthy relationships and sexuality.

**Actions:**

- All PwIDD should have access to research-based, comprehensive, accessible sexuality and relationship education, from childhood through adulthood, in the places where they live and learn.
- Schools, support agencies, and other organizations should review their current sexuality and relationship education programs to ensure they reflect best practice and are accessible to all stakeholders. Programs should include measurable outcomes and effectiveness should be evaluated regularly.

- Research-based sexuality and relationship education should be made a standard and specific part of public special education students' Individualized Education Programs (IEP). At younger ages, this may be included as a goal. At transition age, it should be specified as part of the student's transition plan.
- Post-assault sexuality and relationship education should be made a part of survivors' recovery plans. This education should address safety strategies, relationship boundaries, recovery strategies, and healthy relationships post-assault.

Legislation and policy must also work to mitigate the factors that place PwIDD at risk and must reflect their experiences, views, and needs. We know why people are assaulted—the risk factors are many and clear. Any legislative or policy effort to prevent sexual assault of PwIDD must reflect the reality of and focus on mitigating these risk factors.

**Actions**

- Any agency that serves PwIDD and/or has responsibility around the prevention of and response to sexual assault should critically examine its policies and procedures to remove explicit and implicit roadblocks to justice and recovery. This analysis should consider, among other institution-specific factors, biases, barriers to accessibility, under-staffing and under-resourcing, lack of training or education, and inconsistent policy implementation within and across agencies. It should place the self-advocate at the center of this analysis and any resulting activities.
- Laws and regulations should be adopted that focus on preventing the perpetrator from assaulting, rather than simply preventing the survivor from being assaulted. This could include, for example, the expansion of state registries of direct care staff credibly accused of sexual assault or abuse (currently used in 27 states). It could also include strengthening regulatory requirements for congregate care facilities around prevention of and response to sexual assault of residents.

### *Reporting*

Reporting is perhaps the most problematic and disturbing point on the sexual assault prevention and response continuum for PwIDD. Multiple silencing factors result in few assaults ever being reported. Self-advocates may not know how to report or may fail to report due to fear of retaliation, discrimination, poor treatment, and the stigma associated with sexual assault. The perpetrator—most often a person known to the survivor—may be someone the PwIDD depends on for daily living. The survivor may not report because they fear loss of independence or of needed support. Often, when PwIDD report their assaults in congregate living situations, policies and procedures followed by staff result in no report or long reporting delays that make successful adjudication unlikely. The longer these crimes are not reported, the better chance the assaults will be repeated, and the perpetrator may move on to other victims as well.

**Actions**

- Agencies and organizations that serve PwIDD and are in a position to report sexual assault should confront any internal biases that might lead to survivors not being believed, to having

their experiences belittled or discounted, and to suffering negative consequences due to their assault.

- Congregate care facilities should conduct thorough audits of the policies and procedures that may explicitly or implicitly result in failure to recognize or address sexual assault or in mistreatment of survivors who have experienced assault, including internal reporting and investigatory pathways as well as information and training provided to staff and clients.

Most chilling is that laws and systems intended to protect the most vulnerable people can often work in opposition to this goal, leaving PwIDD at greater risk, especially if they are part of a further marginalized group or are dependent on their abuser. Because of mandatory reporting laws, in many cases the survivor has no choice but to have their assault reported. However, due to an extreme lack of system capacity, adult protective service agencies tasked with the critical job of investigating reports often either fail to investigate or fail to do so in an effective manner that could lead to the arrest and conviction of the perpetrator. Thus, the survivor and the perpetrator may continue to be in close proximity. This leaves the survivor with no protection from the perpetrator. It also may embolden the perpetrator, who now knows they were reported but suffered no consequences. In the absence of the possibility of justice and protection for the survivor, can we—in good conscience—encourage increased reporting of these crimes?

**Actions**

- Adult protective service agencies must be held to account for their systemic failures to investigate sexual assault fully and effectively against PwIDD through top-down review and remediation activities that address biases, accessibility, and capacity.
- The factors that contribute to lack of capacity in these agencies must be confronted and addressed by agency staff, policymakers, and lawmakers, including, for example, improved case manager working conditions, reduced caseloads, and better and required training on working with PwIDD.
- Mandatory reporting laws and their unintended, sometimes harmful consequences must be examined and refined to ensure that they truly protect the most vulnerable. At a minimum, they should emphasize survivor choice and control. Ideally, they should incorporate stopgap measures to ensure survivor safety and well-being throughout the reporting process, and particularly when a report does not result in an arrest or conviction.

### *First Response*

The quality of first response often determines the future adjudication and recovery outcomes of sexual assault cases. When done properly, survivor interviews, examinations, and evidence collection can arm prosecutors with the tools they need to ensure justice is served. The stakes are high. As previously described, unsuccessful adjudication of a sexual assault case often places the perpetrator back in close proximity to the survivor. In addition, the survivor may be retraumatized by a process that fails to recognize their right to equal treatment and equal justice.

However, research reveals that first response to reports of sexual assault of PwIDD are seldom sensitive to the survivors' needs. As a result, critical evidence may fail to be collected or be lost due to untimely collection. Worse, the survivor's story may be discounted or ignored based on deeply held, unexamined biases on the part of the responder. Additionally, survivors are often left without a plan for what happens next—both in terms of their own safety and recovery and in terms of their case. First response that confronts biases, maximizes accessibility, incorporates best practice in evidence collection, and is person-centered can ensure a more successful pathway to justice and the resulting recovery for the survivor.

**Actions**

- Anti-bias and Trauma-Informed Care training should be provided to all first-response personnel, including 911 call operators, EMS personnel, police officers, and emergency room staff. This training should be grounded in best practice and must feature the voices of PwIDD.
- First response agencies should conduct a top-down audit of accessibility policies and procedures to ensure that services are able to be accessed by PwIDD. This should include analysis of physical, communicative, and attitudinal barriers to service and should be conducted with full participation from self-advocates, local agencies, and organizations that serve PwIDD.
- Creative and collaborative solutions that meet short- and long-term needs should be explored. For example, the promising model of including mental health specialists on police calls could be modified such that an advocate for PwIDD responds with police to sexual assault calls involving PwIDD.
- First response agencies should develop, in partnership with local agencies and organizations serving PwIDD, post-assault safety and support plans that are accessible, connect survivors with needed supports, and clarify what will happen next.
- Investigative agencies should analyze and adopt best practice in evidence collection for survivors with IDD, including modifying settings, interviewing techniques, and interview structure in order to improve adjudication outcomes and, thus, survivor recovery.

### *Adjudication*

Allegations of sexual assault perpetrated against PwIDD are rarely substantiated, even more rarely prosecuted, and almost never successfully so. The consequences are dire. Perpetrators are allowed to continue assaulting, survivors are denied recovery, and the sexual assault epidemic remains invisible. The root causes span the continuum—from misconceptions about PwIDD and sexuality, to delays in reporting, to poor evidence collection.

Negative stereotypes about PwIDD in relation to sexuality, cognition, and communication often deter prosecutors from taking these cases. Legal professionals may mistakenly believe that PwIDD are not able to experience sexual assault in the same way people without disabilities do. They may assume a survivor with communication challenges cannot effectively tell their story in court. In addition, laws used to protect PwIDD were often intended for children, which may serve to perpetuate these biases. These beliefs contribute to survivors with IDD being denied justice before they have a chance to access the criminal justice agencies.

**Actions**

- Anti-bias training should be provided to all criminal justice agencies personnel, including investigators, prosecutors, and judges. This training should address biases related to PwIDD's sexuality, cognition, and communication and emphasize that PwIDD can be victimized and can and should access justice as any other survivor of a violent crime.
- Legislative and judicial agencies should evaluate the appropriateness of using laws designed to protect children for use with adults with IDD. Laws that patronize or infantilize PwIDD may perpetuate the very stereotypes that prevent them from accessing justice. They may also omit important protections related to their complex lives as adults that include such aspects as independent living, employment, and having children and family.

Even after the decision is made to move forward with a sexual assault case involving a survivor with IDD, legal representation and legal remedies may be inaccessible to them. This may lead to significant and lifelong consequences, such as lack of needed victim compensation and lack of legal protection remedies that ensure safety and well-being. Yet, research has shown many simple and effective ways to improve accessibility to the criminal justice agencies, such as accessible education about and rehearsal of courtroom processes and procedures and alternative methods of providing testimony.

**Actions**

- Judicial agencies, victim services agencies, IDD agencies, and self-advocates should collaborate to envision and realize an adjudication process that is self-advocate-centered and addresses the intersection of the many aspects of a person's identity. Advocacy is, in and of itself, a healing activity and the survivor's voice should be central in all adjudication activities.
- Judicial agencies should develop and adopt formal accessibility screening and planning tools to ensure that survivors with IDD have equal access to justice. Accessibility may include, for example, plain-language communication, communication support for people who communicate without speech, real-world experiences of the court room prior to trial, role plays of courtroom procedures, alternative modes of giving testimony, and other supports designed to maximize effective participation of the survivor.

### *Survivor Support*

As with any survivor of trauma, survivors of sexual assault who have IDD need a variety of high-quality, individualized supports to aid recovery. While we know much about the practices and tools that are most effective for survivors with IDD, capacity is severely limited. Few mental health professionals are trained to provide needed and effective trauma therapy to PwIDD. Those that would like to learn to provide these services, especially to survivors who do not communicate using speech, have few resources and typically must piece together their own approaches based on intuition and experience. In many cases, practitioners continue to rely on methods and strategies that inappropriately focus on the negative behavior caused by the trauma rather than healing the trauma itself.

**Actions**

- Pockets of theory and practice in treating sexual assault survivors who have IDD should be identified, researched, documented, and expanded. Formal (e.g., university-based) and informal methods of preparing mental health professionals to serve survivors with IDD should be implemented simultaneously and expanded rapidly. This will ensure survivors have access to needed services as quickly as possible, reducing the number of survivors living with untreated trauma.
- Models for providing formal and informal support for survivors with IDD and their families, including one-to-one peer support, facilitated support groups, and community supports, should be developed and implemented through IDD agencies and self-advocacy groups.

As capacity is built around post-assault care for survivors with IDD, efforts must be focused on person-centered practices. PwIDD are diverse, and their different experiences, intersectional identities, and communication abilities require care that is tailored to the individual. In addition, agencies and organizations that provide post-assault care to PwIDD must ensure that their services are fully accessible, removing physical, communication, and other barriers to care.

**Actions**

- Victim services providers should audit their policies and procedures to ensure that services are accessible to PwIDD, incorporating best practice in setting, service intake and delivery methods, and communication modes. They should develop, train staff on, and use formal screening tools to establish survivors' specific needs and accessible ways of meeting those needs.
- Agencies serving PwIDD and agencies serving survivors of sexual assault should collaborate to establish clear and accessible pathways from any point in the system. Cross-training on intake and service delivery can support better and more seamless access to and follow-up of needed services. Agency staff should also establish formal responsibilities for follow-up to ensure that survivors are supported appropriately on an ongoing basis.

## Call to Action

Sexual assault against PwIDD is pervasive, horrific, and largely ignored by society. The disproportionately high rates of sexual assault among PwIDD, the pervasive biases that prevent survivors from accessing justice and recovery, and the insufficient resources brought to bear on this issue at every stage must change. It is often said that society is only as strong as its most vulnerable members. It is time for our society to address the epidemic of sexual assault being perpetrated against PwIDD.

We know and continue to learn where the stressors are and how they confound and reinforce each other. We know that person-centered, accessibility-focused practice at every stage of the sexual assault prevention and response curriculum is critical to making a significant difference. We also know that survivors of sexual assault with IDD are suffering in darkness and silence right now in the absence of effective support. Now is the time to act. We must open our eyes and hearts to this epidemic and its survivors. We must hear their voices in every aspect of the work.

# Methodology

A literature review research design was used to explore and understand the contributing factors to the widespread sexual assault epidemic occurring among PwIDD. The following information describes the research process.

## Sources

The goal of the research was to create a picture of the true scope of the impact of sexual assault perpetrated against PwIDD. To meet this goal, and because so little scientifically-based research is available on this topic, we included a wide variety of sources. When available, sources were taken from peer-reviewed journals. We also analyzed other types of sources including publications from academic, government, news, and non-profit organizations.

In total, 48 resources were used in this project. While the sources were based in the United States, one source from Wales and one source from South Africa were included as they provided a unique view of particular topics. The following is a list of the types and number of resources used:

- academic books: two academic books used
- film: one film used
- government publications: two government agency position papers used
- magazines: one magazine article used
- news sources: 10 news sources used
- nonprofit publications: 17 non-profit organization papers or informational publications used
- scholarly journals: 15 peer-reviewed journal articles used

## Research Process

We developed a research summary form with general categories we planned to explore, which were based on the broad domains along the continuum of sexual assault prevention and response. These domains originally included:

- awareness
- prevention
- reporting
- adjudication
- survivor support

As we reviewed sources, we created a summary form listing the source citation, key points organized by broad topic, and additional sources mentioned that should be added to source list. As research progressed, the topic list evolved based on emerging themes and trends. For example, as we researched, it became apparent that first response was a critical point at which reporting meets adjudication—distinct from both domains in many ways. We felt the importance and unique issues associated with first response warranted a new domain of topics.

Sources used for this project include those focused on people with intellectual and developmental disabilities specifically as well as those addressing people with disabilities more generally. In some sources, these distinctions are less than clear. To improve readability, we generally use the term "people with intellectual and developmental disabilities" (PwIDD). We use the term "people with disabilities" when the source is clear in its inclusion of *all* people with disabilities.

For example, we found there were fewer resources that focused on first response and adjudication as it pertained to PwIDD specifically, so we broadened our focus to include people with all disabilities, while still maintaining an emphasis on PwIDD whenever possible. Similarly, the intersection of marginalized groups with IDD such as people from racially- and ethnically-diverse groups and people from the LGBTQ community also lacked research specific to PwIDD—with the sole exception of the more specific group of transgender people with autism. In these cases, we also expanded our scope to include people with all disabilities, including IDD.

## Participatory Research

From the outset of the project, we were committed to incorporating and expanding on the work done by other researchers in the area of participatory research. Participatory research positions the person with IDD at the center of all research activities. It provides accommodations to ensure PwIDD are included in research design, sourcing, source review, and summarizing. We accomplished this by centering a self-advocate survivor as a key member of our research team. We also included a colleague with whom the self-advocate had previously worked in a participatory process to ensure the self-advocate's comfort and to capitalize on their successful research and development processes.

Research team members met collaboratively via videoconference to set the parameters for research activities. This included selecting meeting frequency, duration, and medium. The team opted to meet weekly for one hour on videoconference. We created tools to facilitate research review during these meetings. We created a slide presentation template with slides organized by domain (awareness, prevention, reporting, first response, adjudication, and survivor support), and included a final slide to address special issues or topics (such as congregate living, people with communication challenges, etc.). We extracted core information from research summaries completed during a one-week period and included further summarized bullets on the appropriate domain slides. Finally, a staff person from our partner organization, University of Massachusetts Medical Center, performed a readability review on the research bullets to further increase their accessibility.

During meetings, the team reviewed key research from the previous week. As we discussed research findings, our self-advocate research team member described how their experiences related to the research. This provided rich context, framing the research in real-world situations. Their feedback was recorded on the slides in real-time, to ensure their perspective was not lost when we synthesized research findings into this framework.

To ensure that the research process remained effective and accessible, we surveyed research team members periodically and anonymously. The Research Team Survey inquired about how well the mechanics of our process (meetings, use of slides, use of videoconferencing) worked for team members,

but also whether the team felt the depth and breadth of research was appropriate, whether members felt the work would make a difference in the world, and whether the work was making a difference in team members' work and lives. Based on feedback gathered at the end of the first quarter of research, we made minor adjustments. For example, team members expressed some uncertainty about whether we were covering enough topics. We adjusted our process to focus more on expanding our research topic list and limited the number of research studies we reviewed for a given topic. For example, a great deal of research discussed sexuality education as a prevention technique. Rather than continuing to incorporate more studies about this topic, we sought to expand into areas that had less research but that the team felt were important—such as intersectionality and peer-based survivor support strategies. Improvements in scores on the second administration of the survey enabled us to confirm that all team members were comfortable with how the work was progressing.

## Listening Sessions

To further enrich the framework and ground it in real-world practice, we convened a series of listening sessions with various stakeholder groups. These groups included:

- self-advocates identifying as sexual assault survivors
- self-advocates not identifying as sexual assault survivors
- self-advocates living in congregate housing
- service coordinators (e.g., LIDDA staff, day habilitation staff)
- first responders

Each listening session explored common themes and issues in sexual assault prevention and response as delineated by our research, with varying levels of emphasis appropriate to each group. These themes and issues included the following.

<u>Awareness</u>

- stigma and silence
- identification and mitigation of risk factors
- recognition of relationship boundaries

<u>Prevention</u>

- sexuality and relationship education
- training and support for professionals

<u>Reporting</u>

- processes and pathways
- mandatory reporting
- safety planning for survivors of sexual assault or abuse

<u>Adjudication</u>

- effectiveness of prosecution

- relationship between law enforcement and people with IDD

Recovery

- recovery needs
- support tools and processes
- Trauma-Informed Care

Sessions were an hour and a half in duration and were held via Zoom during the month of July 2021. Preparation and precautions to ensure the safety and well-being of all participants was extensive and is described in depth—along with example tools and resources—in *Sexual Assault Prevention and Response for People with IDD: A Trauma-Informed Listening Session Protocol*, also produced by this research team. During sessions, a designated note-taker recorded participants' opinions and experiences, and sessions were recorded (with participant agreement). Following each session, the note-taker viewed the sessions again to ensure their notes were complete and accurate; then, all session recordings were destroyed. Findings were summarized in a listening session report and are also included at point-of-use in this framework to enrich, provide context, and demonstrate the impact many of the opportunities and challenges have on stakeholders' lives.

## Framework Domains

The core framework consists of seven domains. Each domain focuses on a specific aspect of the impact of sexual assault on PwIDD, ranging from the risk factors that place PwIDD at increased risk of sexual assault or abuse to best practices for supporting PwIDD who have experienced sexual assault. The seven domains are outlined below.

- *Risk Factors*: This section describes the risk factors that increase a PwIDD's likelihood of being sexually assaulted or abused. Because recognition of these risk factors is so critical in the prevention of sexual assault, we felt a separate section should be included prior to the *Awareness* section. Any person supporting or working with a person with IDD and stakeholder groups involved across the continuum of sexual assault prevention and response must make themselves aware of these risk factors. They should also train themselves to mitigate these risk factors in the lives of their loved ones and/or clients.
- *Awareness*: This section positions sexual assault and abuse as a crimewave being perpetrated against PwIDD, largely in silence. This silence not only leaves survivors unprotected and unsupported, but enables violators to continue harming these survivors, and in some cases to expand their crimes to others. This section describes opportunities that help PwIDD and those who support them to focus greater attention on these issues as well as the challenges that tend to perpetuate inaction.
- *Prevention*: This section explores methods of preventing sexual assault among PwIDD. Comprehensive sexuality and relationship education is a key component to prevention, yet it is often missing in the lives of PwIDD. Other prevention practices include better policy development among service providers and implementing preventative programs through developmental disability agencies.

- *Reporting*: This section addresses the many significant issues that prevent reporting of sexual assault perpetrated against PwIDD. Some of these obstacles arise from cultural and societal expectations that hinder reporting by PwIDD or their families or the inability for PwIDD to communicate what has happened to them. Others result from systemic issues such as pervasive biases, lack of capacity to effectively investigate reports, and institutional silence. This section also examines the rates of underreporting and ways to increase reporting such as recognizing signs of abuse or assault and educating PwIDD on how, when, and why to self-report.
- *First Response*: This section describes a variety of elements important to effective first response to PwIDD who have been sexually assaulted as well as the importance of these approaches. First response that is trauma-informed and person-centered results in better outcomes for the recovery of PwIDD as well as better outcomes for adjudication of these cases. This section addresses first response personnel including emergency room staff, emergency line call takers, EMS, police, and any other specialized personnel likely to have first contact with a sexual assault or abuse survivor.
- *Adjudication*: This section examines the multiple reasons why sexual assault against PwIDD is rarely prosecuted successfully as well as solutions to reverse this dangerous tendency. These solutions include building awareness to overcome cultural biases, education of prosecutors and judges to better understand and work with PwIDD, and education for the adjudication process to prepare PwIDD to go to court.
- *Survivor Support*: This section addresses the many ways PwIDD can be supported after they have experienced sexual assault, which includes such solutions as simply believing the person who has reported their sexual assault to providing appropriate, specialized therapy. Other supports important to recovery include creating a safety plan, recognizing the behaviors survivors may exhibit, and understanding the needs of family members or caregivers who are supporting the survivors.

Through the research process, we also found that specific groups of people or issues are impacted or addressed differently when it comes to sexual assault. We felt special attention to these populations and issues was warranted and created two separate sections to address them.

- *Special Populations*: This section provides information on the diverse needs of PwIDD who have experienced sexual assault. Topics covered here address intersectionality for people in the LGBTQ community, people in racially- and ethnically-marginalized communities, people with autism, children with IDD, transition-aged youth, and people who communicate without speech.
- *Special Issues*: This section addresses issues or settings that significantly impact the experience of PwIDD who have been sexually assaulted. These challenges may complicate issues such as reporting or recovery. These topics include congregate living, reliance on the perpetrator, domestic violence or intimate partner violence, relationships and relationship boundaries, and international issues.

## Opportunities and Challenges

The first seven framework domains each contain two sections labeled *Opportunities* and *Challenges*. Opportunities outline the specific programs, organizations, strategies, and policies that have some evidence of effectiveness or that are recommended by experts in the field. It must be emphasized again

that most of these practices have no research validation in the field. In addition, approaches, tools, and resources listed as opportunities are not necessarily available to PwIDD *right now*. For example, several sources and self-advocates interviewed for this project mention peer support as a positive survivor support tool. Yet, we were unable to find any evidence of such a program, service, or network existing formally in the United States today.

Challenges summarize the deficits that create or maintain status quo with respect to sexual assault and abuse of PwIDD. These may include implicit biases, lack of resources or education, communication challenges, overwhelmed systems, and inaccessible services. Challenges are typically recognized in sources as problematic but do not yet have workable solutions. They are valuable learning points for all those who work or live with PwIDD. Challenges also suggest areas in which additional research or field work is needed.

## Audience Groups

Each framework topic lists one or more audience groups. The audience group specifies either the populations most impacted by the topic and/or the populations most likely to be able to effect change with respect to the topic. Often, more than one audience group is listed, as many issues both impact and are, in turn, impacted by multiple stakeholders. Below are the definitions of the audience groups and a short description of why that audience group might be included with a topic.

- *Self-Advocates*: PwIDD who speak for themselves, make their own decisions, learn about and know their rights, and learn about and know how to find support that is appropriate for their own needs are identified throughout this framework as self-advocates. Self-advocates are listed as an audience because the topic directly relates to their daily living or to special circumstances that impact them directly.
- *Family/Friends/Allies*: People who support PwIDD in their day-to-day lives with no financial compensation are identified throughout this framework as family/friends/allies. These can be parents, siblings, spouses, friends, or any other person close to the self-advocate. Topics where family/friends/allies are listed often contain information about how this group can provide support or access to services or how they themselves can find support.
- *Service Providers*: People who provide or oversee services to self-advocates under a financial exchange are identified throughout this framework as service providers. Examples of service providers include direct care staff, transportation drivers, vocational trainers, respite caregivers, and coordinators of IDD services. When service providers are included as an audience, the topic typically relates to how a service provider can reduce their clients' risk of sexual assault and abuse and how they can impact systemic change at any point in the sexual assault prevention and response continuum.
- *First Responders*: Professionals who are one of the first to interact with survivors of sexual assault are identified throughout this framework as first responder. They may include EMS/EMTs, emergency line call takers, police, and emergency room staff such as Sexual Assault Nurse Examiners (SANE). Topics in this category typically provide information about how these professionals can confront their own biases, make the reporting and investigation process more

accessible and responsive to PwIDD, and improve adjudication outcomes by gathering and preserving evidence.

- *IDD Agencies*: Agencies included in this audience provide services specific to intellectual and developmental needs. This audience is typically referenced when a systemic opportunity or challenge is presented requiring improvement, change, or better implementation of policy.
- *Criminal Justice Agencies*: Agencies included in this audience facilitate justice for survivors of violent crime. This may include, for example, law enforcement agencies and the court system. Typically, these agencies do not offer specialized services to meet the needs of PwIDD but could create effective systemic change that improve their outcomes during the adjudication process.
- *Policymakers*: People or organizations that have the power to research, decide upon, and implement changes within organizations and governments are identified throughout this framework as policymakers. When policymakers are listed as an audience, topics tend to address important issues to consider when proposing, writing, or implementing policy.

## Relevant Statistics

Some framework topics include a *Relevant Statistics* category. Where the research we analyzed quantified impact with data and statistics, we included that information. It should be noted that few topics include this section, as many sources provided anecdotal information or described broad impacts. Lack of statistical information may indicate an area ripe for future research. Relevant statistics were included in the framework to assist policymakers, advocacy groups, and other interested parties to better advocate for policies, tools, and processes to address the epidemic of sexual assault and abuse against PwIDD.

## Special Populations and Special Issues

As previously described, some populations and issues relate to or are impacted by topics across the continuum of sexual assault response, and these are addressed in separate sections of the framework. Where a continuum framework topic intersects one or more *Special Populations* or *Special Issues* sections, we have included a notation. For example, in the *Awareness* section, we have included a section addressing the issue that perpetrators are usually known to the survivor. Because this challenge more significantly impacts people living in congregate care, we have included a reference to the *Special Population* topic, *Congregate Living*. This enables the reader to access more information efficiently and to gain context for the topic.

## How to Use this Framework

The research completed and documented in this framework describes aspects of sexual assault and abuse perpetrated against PwIDD. Some sections are more relevant to specific groups or organizations. For example, *Congregate Living* addresses specific challenges associated with those living in congregate care. *Incomplete or Ineffective Representation* addresses the legal professionals (e.g., prosecutors) representing sexual assault survivors in court. Other topics provide information for anyone affected by sexual assault or abuse. For example, *Stigma* affects any person or group working with survivors of sexual assault as well as survivors themselves. *Implicit Bias* is endemic and hinders positive outcomes at every stage.

The framework was designed with a flexible format that allows readers to use it in a variety of ways. The *Framework at a Glance* section provides concise charts for each domain of the sexual assault and abuse continuum. These charts demonstrate—for each opportunity and challenge—the stakeholder groups, special populations, and special issues associated with the topic. This section can be used to gain a broad view of the landscape of the findings.

Each major section of the framework provides more in-depth information, including a brief overview and narrative text describing each opportunity and challenge more extensively. A reader can review the framework sections from beginning to end to get a big picture view of the impact of sexual assault on PwIDD. Or a reader can read specific sections of interest without losing any context.

We have also designed the framework to lend an organizational structure to entities—state agencies, nonprofit organizations, hospitals, schools, support networks—that wish to evaluate their own policies and practices with respect to how they approach sexual assault perpetrated against PwIDD. Specifically, we recommend:

1. extracting each framework topic to create an outline format (with the understanding that staff can refer to the original, complete framework for more detail about a given topic if needed)
2. annotating and prioritizing this topic list to identify topics that are most directly in the organization's locus of control
3. analyzing and refining laws and regulations, formal and informal policies and procedures, and attitudes and beliefs of the organization that either promote positive outcomes related to sexual assault or abuse of PwIDD at each stage of the continuum
4. implementing practices to improve positive outcomes, such as through stakeholder surveys, staff or stakeholder training, regulatory and policy changes, etc.

In this way, the framework can become a living document that compels entities to better understand the needs of PwIDD and the effects of sexual assault and abuse on them and to adapt their own systems and organizations to effect positive change.

## Framework at a Glance

| **Risk Factors** | Challenges | | | |
|---|---|---|---|---|
| | Type or Severity of Disability | Speech and Communication Difficulties | Learned Compliance | Lack of Understanding of Boundaries |
| **Stakeholders** | | | | |
| Self-Advocates | ● | ● | ● | ● |
| Family/Friends/Allies | ● | ● | ● | ● |
| Service Providers | ● | ● | ● | ● |
| First Responders | ● | ● | ● | ● |
| IDD Agencies | ● | ● | ● | ● |
| Criminal Justice Agencies | ● | ● | ● | ● |
| Policymakers | ● | ● | ● | ● |
| **Special Populations** | | | | |
| LGBTQ Community | | | | |
| Racially- and Ethnically-Marginalized Communities | | | | |
| People With Autism | ● | | | |
| Children With IDD | | | ● | |
| Transition-Aged Youth | | | | |
| PwIDD Who Communicate Without Speech | ● | ● | | |
| **Special Issues** | | | | |
| Congregate Living | | | ● | ● |
| Reliance on the Perpetrator | | | | ● |
| Domestic and Intimate Partner Violence | | | | |
| Relationships and Relationship Boundaries | | | ● | ● |
| International Issues | | | | |

| **Risk Factors** | Challenges | | |
|---|---|---|---|
| | Desire for Friendship or Romantic Relationships | Known Perpetrators and Grooming | Congregate Living |
| **Stakeholders** | | | |
| Self-Advocates | ● | ● | ● |
| Family/Friends/Allies | ● | ● | ● |
| Service Providers | ● | ● | ● |
| First Responders | ● | ● | ● |
| IDD Agencies | ● | ● | ● |
| Criminal Justice Agencies | ● | ● | ● |
| Policymakers | ● | ● | ● |
| **Special Populations** | | | |
| LGBTQ Community | | | |
| Racially- and Ethnically-Marginalized Communities | | | |
| People With Autism | | | |
| Children With IDD | | | |
| Transition-Aged Youth | | | |
| PwIDD Who Communicate Without Speech | | | |
| **Special Issues** | | | |
| Congregate Living | | ● | ● |
| Reliance on the Perpetrator | ● | ● | |
| Domestic and Intimate Partner Violence | ● | | |
| Relationships and Relationship Boundaries | ● | ● | |
| International Issues | | ● | ● |

| **Awareness** | Opportunities | | |
|---|---|---|---|
| | Awareness-Building Campaigns | Assessment and Intake Tools for PwIDD | Anti-Bias Activities |
| **Stakeholders** | | | |
| Self-Advocates | ● | | ● |
| Family/Friends/Allies | ● | | ● |
| Service Providers | ● | ● | ● |
| First Responders | | ● | ● |
| IDD Agencies | ● | ● | ● |
| Criminal Justice Agencies | | ● | ● |
| Policymakers | | | ● |
| **Special Populations** | | | |
| LGBTQ Community | ● | | |
| Racially- and Ethnically-Marginalized Communities | ● | | |
| People With Autism | | | |
| Children With IDD | | | ● |
| Transition-Aged Youth | | | |
| PwIDD Who Communicate Without Speech | | | ● |
| **Special Issues** | | | |
| Congregate Living | | | |
| Reliance on the Perpetrator | | | |
| Domestic and Intimate Partner Violence | | ● | |
| Relationships and Relationship Boundaries | | | |
| International Issues | | | ● |

| **Awareness** | Challenges | |
|---|---|---|
| | Failure to Recognize Signs of Abuse | Intersectional Biases |
| **Stakeholders** | | |
| Self-Advocates | ● | ● |
| Family/Friends/Allies | ● | ● |
| Service Providers | ● | ● |
| First Responders | ● | ● |
| IDD Agencies | ● | ● |
| Criminal Justice Agencies | ● | ● |
| Policymakers | ● | ● |
| **Special Populations** | | |
| LGBTQ Community | | ● |
| Racially- and Ethnically-Marginalized Communities | | ● |
| People With Autism | ● | |
| Children With IDD | ● | |
| Transition-Aged Youth | | |
| PwIDD Who Communicate Without Speech | ● | |
| **Special Issues** | | |
| Congregate Living | ● | |
| Reliance on the Perpetrator | | |
| Domestic and Intimate Partner Violence | | ● |
| Relationships and Relationship Boundaries | ● | |
| International Issues | ● | |

| **Prevention** | Opportunities | | | |
|---|---|---|---|---|
| | Sexuality and Relationship Education | Post-Assault Sexuality and Relationship Education | Sexuality Education in Transition Planning | State and National Actions |
| **Stakeholders** | | | | |
| Self-Advocates | ● | ● | ● | ● |
| Family/Friends/Allies | ● | ● | ● | ● |
| Service Providers | ● | ● | ● | ● |
| First Responders | | | | |
| IDD Agencies | | | | ● |
| Criminal Justice Agencies | | | | ● |
| Policymakers | | | | ● |
| **Special Populations** | | | | |
| LGBTQ Community | ● | | | |
| Racially- and Ethnically-Marginalized Communities | | | | |
| People With Autism | | | | |
| Children With IDD | | ● | | |
| Transition-Aged Youth | ● | ● | ● | ● |
| PwIDD Who Communicate Without Speech | | | | |
| **Special Issues** | | | | |
| Congregate Living | | | | ● |
| Reliance on the Perpetrator | | | | ● |
| Domestic and Intimate Partner Violence | | | | |
| Relationships and Relationship Boundaries | ● | ● | | |
| International Issues | | | | |

| **Prevention** | Challenges | |
|---|---|---|
| | Barriers to Effective Sexuality Education | Lack of Inclusive and Consistent Policy |
| **Stakeholders** | | |
| Self-Advocates | ● | ● |
| Family/Friends/Allies | ● | ● |
| Service Providers | ● | ● |
| First Responders | | |
| IDD Agencies | | ● |
| Criminal Justice Agencies | | ● |
| Policymakers | | ● |
| **Special Populations** | | |
| LGBTQ Community | ● | |
| Racially- and Ethnically-Marginalized Communities | | |
| People With Autism | ● | |
| Children With IDD | | |
| Transition-Aged Youth | ● | |
| PwIDD Who Communicate Without Speech | | |
| **Special Issues** | | |
| Congregate Living | | |
| Reliance on the Perpetrator | | |
| Domestic and Intimate Partner Violence | | |
| Relationships and Relationship Boundaries | ● | |
| International Issues | | |

| **Reporting** | Opportunities | |
|---|---|---|
| | Autonomy and Choice for Survivors | Legal Protections for PwIDD |
| Stakeholders | | |
| Self-Advocates | ● | ● |
| Family/Friends/Allies | ● | ● |
| Service Providers | ● | ● |
| First Responders | ● | ● |
| IDD Agencies | | |
| Criminal Justice Agencies | ● | ● |
| Policymakers | | |
| Special Populations | | |
| LGBTQ Community | ● | |
| Racially- and Ethnically-Marginalized Communities | ● | |
| People With Autism | | |
| Children With IDD | ● | |
| Transition-Aged Youth | | |
| PwIDD Who Communicate Without Speech | | |
| Special Issues | | |
| Congregate Living | ● | |
| Reliance on the Perpetrator | | |
| Domestic and Intimate Partner Violence | ● | |
| Relationships and Relationship Boundaries | | |
| International Issues | | |

| **Reporting** | Challenges | | | |
|---|---|---|---|---|
| | Not Knowing How to Report | Stigma | Mistrust and Fear of Law Enforcement | Fear of Negative Consequences |
| **Stakeholders** | | | | |
| Self-Advocates | ● | ● | ● | ● |
| Family/Friends/Allies | ● | ● | ● | ● |
| Service Providers | ● | ● | ● | ● |
| First Responders | | ● | ● | ● |
| IDD Agencies | | | | ● |
| Criminal Justice Agencies | | | ● | ● |
| Policymakers | | | | |
| **Special Populations** | | | | |
| LGBTQ Community | | ● | | |
| Racially- and Ethnically-Marginalized Communities | | ● | ● | ● |
| People With Autism | | | | |
| Children With IDD | | ● | | |
| Transition-Aged Youth | | | | |
| PwIDD Who Communicate Without Speech | | | | |
| **Special Issues** | | | | |
| Congregate Living | ● | ● | | ● |
| Reliance on the Perpetrator | | ● | | ● |
| Domestic and Intimate Partner Violence | | | | ● |
| Relationships and Relationship Boundaries | | | | ● |
| International Issues | | | | |

| **Reporting** | Challenges | | |
|---|---|---|---|
| | Law Enforcement and Agency Bias | Institutional Silence | Mandatory Reporting and Adult Protective Services |
| **Stakeholders** | | | |
| Self-Advocates | ● | ● | ● |
| Family/Friends/Allies | ● | ● | ● |
| Service Providers | | ● | ● |
| First Responders | ● | ● | ● |
| IDD Agencies | | ● | ● |
| Criminal Justice Agencies | ● | ● | ● |
| Policymakers | | ● | ● |
| **Special Populations** | | | |
| LGBTQ Community | ● | | |
| Racially- and Ethnically-Marginalized Communities | ● | | |
| People With Autism | | | |
| Children With IDD | | | |
| Transition-Aged Youth | | | |
| PwIDD Who Communicate Without Speech | ● | | |
| **Special Issues** | | | |
| Congregate Living | | ● | |
| Reliance on the Perpetrator | | | |
| Domestic and Intimate Partner Violence | ● | | |
| Relationships and Relationship Boundaries | | | |
| International Issues | | | |

| **First Response** | Opportunities | | | |
|---|---|---|---|---|
| | Understanding Barriers to Reporting | Empathy and Trust | Trauma-Informed Care | Person-Centered First Response |
| **Stakeholders** | | | | |
| Self-Advocates | | ● | | ● |
| Family/Friends/Allies | | ● | | ● |
| Service Providers | | ● | ● | ● |
| First Responders | ● | ● | ● | ● |
| IDD Agencies | | ● | | |
| Criminal Justice Agencies | ● | ● | ● | ● |
| Policymakers | | | | |
| **Special Populations** | | | | |
| LGBTQ Community | ● | | | ● |
| Racially- and Ethnically-Marginalized Communities | ● | | | ● |
| People With Autism | | | | |
| Children With IDD | | | | |
| Transition-Aged Youth | | | | |
| PwIDD Who Communicate Without Speech | | | | ● |
| **Special Issues** | | | | |
| Congregate Living | ● | | ● | |
| Reliance on the Perpetrator | ● | | | ● |
| Domestic and Intimate Partner Violence | | | | |
| Relationships and Relationship Boundaries | | | | |
| International Issues | | | | |

| **First Response** | Opportunities | | Challenges |
|---|---|---|---|
| | Ready Support and Service Referrals | Implicit Bias | Implicit Bias |
| Stakeholders | | | |
| Self-Advocates | ● | ● | ● |
| Family/Friends/Allies | ● | ● | ● |
| Service Providers | ● | | |
| First Responders | ● | ● | ● |
| IDD Agencies | | | |
| Criminal Justice Agencies | | ● | ● |
| Policymakers | | | |
| Special Populations | | | |
| LGBTQ Community | | | |
| Racially- and Ethnically-Marginalized Communities | | | |
| People With Autism | | | |
| Children With IDD | | ● | ● |
| Transition-Aged Youth | | | |
| PwIDD Who Communicate Without Speech | | ● | ● |
| Special Issues | | | |
| Congregate Living | | | |
| Reliance on the Perpetrator | ● | | |
| Domestic and Intimate Partner Violence | ● | | |
| Relationships and Relationship Boundaries | | | |
| International Issues | | | |

| **Adjudication** | Opportunities | | | |
|---|---|---|---|---|
| | Self-Advocacy and Inclusion | Accessibility Planning and Screening | Preparation of PwIDD for Court Proceedings | Alternate Methods of Testimony from PwIDD |
| Stakeholders | | | | |
| Self-Advocates | ● | ● | ● | ● |
| Family/Friends/Allies | ● | ● | ● | ● |
| Service Providers | | | | |
| First Responders | | | | |
| IDD Agencies | | | | |
| Criminal Justice Agencies | ● | ● | ● | ● |
| Policymakers | | | | |
| Special Populations | | | | |
| LGBTQ Community | | | | |
| Racially- and Ethnically-Marginalized Communities | | | | |
| People With Autism | | | | |
| Children With IDD | | | | |
| Transition-Aged Youth | | | | |
| PwIDD Who Communicate Without Speech | | ● | | |
| Special Issues | | | | |
| Congregate Living | | | | |
| Reliance on the Perpetrator | | | | |
| Domestic and Intimate Partner Violence | | | | |
| Relationships and Relationship Boundaries | | | | |
| International Issues | | ● | ● | ● |

| **Adjudication** | Opportunities | |
|---|---|---|
| | Better Prosecution Tools | Service Provider Advocacy |
| Stakeholders | | |
| Self-Advocates | ● | ● |
| Family/Friends/Allies | ● | ● |
| Service Providers | | ● |
| First Responders | | |
| IDD Agencies | | |
| Criminal Justice Agencies | ● | ● |
| Policymakers | | |
| Special Populations | | |
| LGBTQ Community | | |
| Racially- and Ethnically-Marginalized Communities | | |
| People With Autism | | |
| Children With IDD | | |
| Transition-Aged Youth | | |
| PwIDD Who Communicate Without Speech | | |
| Special Issues | | |
| Congregate Living | | |
| Reliance on the Perpetrator | | |
| Domestic and Intimate Partner Violence | | |
| Relationships and Relationship Boundaries | | |
| International Issues | ● | |

| **Adjudication** | Challenges | | | |
|---|---|---|---|---|
| | Inability to Substantiate Assault or Abuse | Reporting Delays | Prejudice | Repeat Offenders |
| **Stakeholders** | | | | |
| Self-Advocates | ● | ● | ● | ● |
| Family/Friends/Allies | ● | ● | ● | ● |
| Service Providers | ● | ● | ● | ● |
| First Responders | | | | |
| IDD Agencies | | | | |
| Criminal Justice Agencies | ● | ● | ● | ● |
| Policymakers | | | | |
| **Special Populations** | | | | |
| LGBTQ Community | | | | |
| Racially- and Ethnically-Marginalized Communities | | | | |
| People With Autism | | | ● | |
| Children With IDD | | | | |
| Transition-Aged Youth | | | | |
| PwIDD Who Communicate Without Speech | ● | ● | ● | |
| **Special Issues** | | | | |
| Congregate Living | ● | ● | | ● |
| Reliance on the Perpetrator | ● | | | ● |
| Domestic and Intimate Partner Violence | ● | | | |
| Relationships and Relationship Boundaries | | | | |
| International Issues | | | | |

| **Adjudication** | Challenges | | | |
|---|---|---|---|---|
| | Repeat Offenders | Unclear Offenders | Laws Designed for Juvenile Justice | Incomplete or Ineffective Representation |
| **Stakeholders** | | | | |
| Self-Advocates | ● | ● | ● | ● |
| Family/Friends/Allies | ● | ● | ● | ● |
| Service Providers | ● | ● | ● | |
| First Responders | | | | |
| IDD Agencies | | | | |
| Criminal Justice Agencies | ● | ● | ● | ● |
| Policymakers | | | | |
| **Special Populations** | | | | |
| LGBTQ Community | | | | |
| Racially- and Ethnically-Marginalized Communities | | | | |
| People With Autism | | | | |
| Children With IDD | | | | |
| Transition-Aged Youth | | | | |
| PwIDD Who Communicate Without Speech | | ● | | |
| **Special Issues** | | | | |
| Congregate Living | ● | ● | | |
| Reliance on the Perpetrator | ● | | | |
| Domestic and Intimate Partner Violence | | | | |
| Relationships and Relationship Boundaries | | | | |
| International Issues | | | | |

| **Survivor Support** | Opportunities | | | |
|---|---|---|---|---|
| | Education About Survivors With IDD | Accessible Support Services | Intersectional Approaches | Recognizing and Mitigating Trauma Triggers |
| Stakeholders | | | | |
| Self-Advocates | ● | ● | ● | ● |
| Family/Friends/Allies | ● | ● | ● | ● |
| Service Providers | ● | ● | ● | ● |
| First Responders | | ● | ● | |
| IDD Agencies | ● | ● | ● | |
| Criminal Justice Agencies | ● | | | |
| Policymakers | | | ● | |
| Special Populations | | | | |
| LGBTQ Community | | | ● | |
| Racially- and Ethnically-Marginalized Communities | | | ● | |
| People With Autism | | | ● | |
| Children With IDD | | | | |
| Transition-Aged Youth | | | | |
| PwIDD Who Communicate Without Speech | | | ● | |
| Special Issues | | | | |
| Congregate Living | ● | | | |
| Reliance on the Perpetrator | ● | | | |
| Domestic and Intimate Partner Violence | | | | |
| Relationships and Relationship Boundaries | | | | |
| International Issues | | | | |

| **Survivor Support** | Opportunities | | | |
|---|---|---|---|---|
| | Safety Planning | Family/ Caregiver Support | Natural Supports | Peer Support |
| Stakeholders | | | | |
| Self-Advocates | ● | ● | ● | ● |
| Family/Friends/Allies | ● | ● | ● | ● |
| Service Providers | ● | ● | ● | ● |
| First Responders | ● | | | |
| IDD Agencies | ● | ● | ● | ● |
| Criminal Justice Agencies | | | | |
| Policymakers | | | | |
| Special Populations | | | | |
| LGBTQ Community | | | | |
| Racially- and Ethnically-Marginalized Communities | | | | |
| People With Autism | | | | |
| Children With IDD | | | | |
| Transition-Aged Youth | | | | |
| PwIDD Who Communicate Without Speech | | | | |
| Special Issues | | | | |
| Congregate Living | ● | | | |
| Reliance on the Perpetrator | ● | | | |
| Domestic and Intimate Partner Violence | ● | | | |
| Relationships and Relationship Boundaries | | | | |
| International Issues | | | | |

| **Survivor Support** | Opportunities | | | |
|---|---|---|---|---|
| | Survivor Support Groups | Psychotherapy | Legislative Protections | Advocacy |
| **Stakeholders** | | | | |
| Self-Advocates | ● | ● | ● | ● |
| Family/Friends/Allies | ● | ● | ● | |
| Service Providers | ● | ● | ● | |
| First Responders | | | ● | |
| IDD Agencies | ● | ● | ● | |
| Criminal Justice Agencies | | | ● | |
| Policymakers | | | ● | |
| **Special Populations** | | | | |
| LGBTQ Community | | | | |
| Racially- and Ethnically-Marginalized Communities | | | | |
| People With Autism | | ● | | |
| Children With IDD | | ● | ● | |
| Transition-Aged Youth | | | ● | |
| PwIDD Who Communicate Without Speech | | | | |
| **Special Issues** | | | | |
| Congregate Living | | | | |
| Reliance on the Perpetrator | | | ● | |
| Domestic and Intimate Partner Violence | | | ● | |
| Relationships and Relationship Boundaries | | | | |
| International Issues | | | | |

| **Survivor Support** | Challenges | |
|---|---|---|
| | Punitive Approaches to Sexual Assault | Lack of Specialized Therapy |
| **Stakeholders** | | |
| Self-Advocates | ● | ● |
| Family/Friends/Allies | ● | ● |
| Service Providers | ● | ● |
| First Responders | ● | |
| IDD Agencies | ● | ● |
| Criminal Justice Agencies | | |
| Policymakers | | |
| **Special Populations** | | |
| LGBTQ Community | | |
| Racially- and Ethnically-Marginalized Communities | | |
| People With Autism | | |
| Children With IDD | ● | ● |
| Transition-Aged Youth | | |
| PwIDD Who Communicate Without Speech | ● | |
| **Special Issues** | | |
| Congregate Living | ● | |
| Reliance on the Perpetrator | | |
| Domestic and Intimate Partner Violence | | |
| Relationships and Relationship Boundaries | | |
| International Issues | | |

# Core Framework

## Risk Factors

People with disabilities experience victimization at significantly higher rates than people without disabilities. Research has revealed sobering statistics to support this statement.

- People with disabilities may be 300 times more at risk for sexual assault than are people without disabilities. One study indicated 60% of the people surveyed reported emotional, physical, sexual, and/or disability-related abuse. This number is likely an underestimate since many participants in the study declined to answer this question (Hughes et al., 2020).
- Another study reports PwIDD are seven times more likely to experience sexual assault or abuse than people without disabilities. This number is limited to people aged 12 and older and *does not include people living in institutions or group homes*, which means that this number is likely significantly much higher (Shapiro, 2018a).
- From 2010 to 2014, PwIDD experienced rates of total violent crime (56.6 per 1,000), serious violent crime (24.0 per 1,000), and simple assault (32.6 per 1,000). Children with developmental delays had four times the risk of experiencing sexual assault (Smith et al., 2017).
- PwIDD are more likely to experience repeated abuse. One study indicated that 49% of people will experience 10 or more incidents of abuse in their lifetime (National Association of Councils on Developmental Disabilities, 2017)
- Research shows more than 90% of people with intellectual disabilities will experience some type of sexual abuse, and it is estimated that at least 15,000 to 19,000 people with intellectual disabilities are sexually assaulted each year in the United States (National Association of Councils on Developmental Disabilities, 2017).
- Risk of assault and abuse is heightened for men and women alike. For example, a physician who works exclusively with PwIDD estimates that at least half of the women she sees have been sexually assaulted (Shapiro, 2018c). Rates of sexual assault against men with a disability are 14%, while only 4% for men without a disability (Smith et al., 2017).

Professionals who work with sexual assault or abuse survivors are likely to encounter PwIDD. However, they are typically not trained or prepared to assist with these cases. The first responder participating in the listening session for this project indicated that people in their field are uncomfortable with sexual assault issues related to any marginalized groups, including PwIDD. They felt training was the most critical tool in changing this situation.

Similarly, it is likely that those who support PwIDD such as service providers, healthcare providers, family, and friends will be in a position to recognize, address, and provide support for a PwIDD who has experienced sexual assault or abuse. It is therefore increasingly important that anyone who lives, works, or spends time with PwIDD understands the intersection of survivors of sexual assault or abuse and disability. This awareness will ensure effective and safe intervention (Vera Institute of Justice, 2020c).

The specific factors described in the research and detailed in this section can be grouped into a few broad categories.

- aspects of PwIDD's identities—whether inherent or cultivated by others—that can be exploited by perpetrators and inhibit discovery of victimization
- desire of PwIDD for relationships confounded with a lack of information or education about healthy boundaries
- isolating factors that segregate PwIDD from community and increase exposure to and reliance on potential abusers

This section explores the specific risk factors within these broad categories that may worsen or complicate PwIDD's overall risk for sexual assault or abuse. Understanding these factors can help PwIDD and the people who live and work with them be better positioned to prevent assault or abuse and address it effectively if it happens.

## Challenges

### *Type or Severity of Disability*

People with disabilities are over three times more likely to experience serious violent crimes, which include rape and sexual assault. Having multiple disabilities puts a person at higher risk of rape and sexual assault, with one survey indicating 69% of people with disabilities who were sexually assaulted had multiple disabilities (Smith et al., 2017). In addition, people with more profound disabilities and higher support needs are more likely to be abused (National Association of Councils on Developmental Disabilities, 2017).

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, IDD Agencies, First Responders, Criminal Justice Agencies, Policymakers

Special Populations/Issues: PwIDD Who Communicate Without Speech, People with Autism

### *Speech and Communication Difficulties*

Limited speech and compromised communication abilities impact PwIDD in many ways with respect to sexual assault and abuse. In general, they make PwIDD more vulnerable to sexual assault. (Shapiro, 2018a). In addition, many PwIDD are not able to give consent to sexual relationships because of cognitive and/or communication limitations. Sexual relationships in these situations could be against the law (Pennsylvania Coalition Against Rape, n.d.). Finally, speech and communication difficulties can make it challenging to substantiate allegations of abuse (Shapiro, 2018e).
Additionally, assessment and treatment of the trauma experienced from sexual assault is woefully inadequate for PwIDD who communicate without speech (Miller, 2021). Diagnosis for PTSD or other trauma-related disorders often relies on verbal communication, which is difficult if not impossible for a person who communicates without speech (Daveney et al., 2019; Kildahl et al., 2020a; Kildahl

et al., 2020b). Diagnosis that is dependent on symptom presentation may also be hindered by diagnostic overshadowing, with PTSD symptoms mistakenly viewed as psychosis (Mevissen et al., 2016).

If a PwIDD who communicates without speech is recognized as having PTSD or another trauma-related disorder, there are almost no treatments available. A 2013 study of PwIDD who communicate with some or no speech who experienced trauma reported that no participant found a therapeutic technique that was successful in treating their trauma (Rowsell et al., 2013). Recent research, however, has reported positive results for treating trauma that occurs in PwIDD who communicate without speech using eye movement desensitization and reprocessing (EMDR) therapy (McNally et al., 2021; Mevissen et al., 2012; Mevissen et al., 2016).

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, IDD Agencies, First Responders, Criminal Justice Agencies, Policymakers

Special Populations/Issues: PwIDD Who Communicate Without Speech

### *Learned Compliance*

People with disabilities are taught to be compliant. From an early age, they are taught to listen to and rely on the adults without disabilities around them. This opens them up to the possibility of being sexually assaulted. It may also give the false perception that the person is weak and an easy target for assault (Pennsylvania Coalition Against Rape, n.d.; Shapiro, 2018g).

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, IDD Agencies, First Responders, Criminal Justice Agencies, Policymakers

Special Populations/Issues: Children With IDD, Congregate Living, Relationships and Relationship Boundaries

### *Lack of Understanding of Boundaries*

PwIDD may not know what sexual assault is or that it is against the law. Many people with disabilities may not have a clear understanding of relationship boundaries (Pennsylvania Coalition Against Rape, n.d.). While some self-advocates interviewed for this project reported that they feel they understand relationship boundaries, some expressed confusion. One self-advocate described having difficulties understanding boundaries at work. Another self-advocate related to this experience, stating that they sometimes get mixed signals related to coworker, friend, and romantic boundaries. Self-advocates in congregate housing stated that it is easier to maintain boundaries in their group home due to their friendships, but that they are sometimes unsure about boundaries with service providers who may come into their home.

One self-advocate survivor stated that they knew very little about boundaries and relationships before the assault they experienced. They described allowing a person to touch them on their private parts because they did not realize that this was inappropriate. After reading a book, they

better understood social boundaries. Another self-advocate survivor discussed the lack of boundaries in their life, including that their father molested them from a young age and taught them that sex is love. They reported not having the word “no” in their vocabulary until they were in their 20s. They stated that they believe in the need to educate young people about boundaries to protect them from abuse.

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, IDD Agencies, First Responders, Criminal Justice Agencies, Policymakers

Special Populations/Issues: Congregate Living, Reliance on Perpetrator, Relationships and Relationship Boundaries

### *Desire for Friendship or Romantic Relationships*

A strong desire for friendship and romantic relationships can be a contributing factor to sexual assault risk (Shapiro, 2018c; Shapiro, 2018d). For example, in a case that took place in Glen Ridge, New Jersey, members of a school football team raped a young woman with IDD. During the trial, it became clear that the young woman had no friends but desperately wanted them, including some of the boys who assaulted her. She did not understand the difference between love and sex. She did not understand that she could say no to boys asking for sex (Shapiro, 2018e). Similarly, a teacher of a sex education class for PwIDD has found that her students want relationships that include love, sex, romance, and support. They want relationships similar to those of their parents, siblings, and friends (Shapiro, 2018d).

The self-advocate working on this project added that some PwIDD may not have a clear sense of what appropriate affection is because their parents may not have demonstrated it to them. In addition, some people may want affection so badly they may not recognize when affection becomes inappropriate. Or they may go along with it just to get any kind of affection.

Abusers may exploit this desire in order to perpetrate sexual assault. For example, they may tell the PwIDD that they are a boyfriend or girlfriend to try to coax the person into having sex (Shapiro, 2018f). The self-advocate working on this project affirmed that PwIDD have this desire—and rightfully so—but that it sometimes makes them easy targets for people who know of their desire for connection and can exploit their confusion around appropriate boundaries.

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, IDD Agencies, First Responders, Criminal Justice Agencies, Policymakers

Special Populations/Issues: Reliance on Perpetrator, Domestic and Intimate Partner Violence, Relationships and Relationship Boundaries

### *Known Perpetrators and Grooming*

Almost all abuse committed against people with disabilities is done by someone the individual knows. This may be as prevalent as 96% of cases of abuse (National Association of Councils on

Developmental Disabilities, 2017). PwIDD are most often sexually assaulted by other people with IDD, service providers, relatives, or friends (Shapiro, 2018a). Sometimes the person entrusted to care for the PwIDD can be the abuser, such as a caregiver or someone who drives the PwIDD to appointments or work. PwIDD who have been sexually assaulted report feeling dirty and blaming themselves after the assault, and they describe being treated with kindness prior to the assault by the person who assaulted them (Shapiro, 2018g).

At times, abuse may be going on in the family, but the PwIDD chooses not to report for various reasons. For example, in one case of a man with IDD who was HIV positive, he did not report that his stepfather had abused him until his sister and her two children moved into the home. The man reported the abuse in order to protect the two children from experiencing what he had (Shapiro, 2018f).

Relevant Statistics:

- Women with IDD are sexually assaulted by a stranger less than 14% of the time, compared to women without a disability (24% of the time; Shapiro, 2018a).
- In 2016, in over 500 cases of suspected sexual abuse in Pennsylvania, 42% of suspected offenders were other PwIDD, 14% were staff, 12% were relatives, and 11% were friends (Shapiro, 2018a).
- For PwIDD, sexual assaults happen during the day more often than for those without disabilities (50%, compared to 40% of the time for people without disabilities). PwIDD are vulnerable everywhere, including where they live, work, go to school, on rides to appointments, and in public places (Shapiro, 2018a).

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, IDD Agencies, First Responders, Criminal Justice Agencies, Policymakers

Special Populations/Issues: Congregate Living, Reliance on Perpetrator, Relationships and Relationship Boundaries, International Issues

### *Congregate Living*

Most incidents of abuse and neglect for PwIDD go unreported, especially for people in congregate settings, where unreported abuse may be as high as 85% (National Association of Councils on Developmental Disabilities, 2017). The United States Justice Department estimates PwIDD are at least seven times more likely to experience sexual assault, yet this figure does not take into consideration the people living in group homes or state institutions where vulnerability to sexual assault is much higher (Shapiro, 2018a). High turnover in residential programs exacerbates the problem. For example, new staff may be bathing people with disabilities within hours of meeting them (Pennsylvania Coalition Against Rape, n.d.).

Worldwide, young women living in institutions frequently have their rights violated regarding what happens to their bodies, including being subjected to forced abortions, forced sterilizations,

exposure to sexually transmitted infections (STI) and sexual violence (United Nations Population Fund, 2018). The United States has a history in the 20th century of institutionalizing women who were thought to have intellectual disabilities and implementing forced sterilization (Shapiro, 2018d).

Self-advocates interviewed for this project who live in congregate housing reported varying levels of information and support provided by those overseeing the home. One self-advocate reported that their group home had a phone number posted in common areas so residents could call to report abuse. Other self-advocates stated that they did not have written guidelines to reporting in their group home and believed it would be helpful to them if they did.

Service coordinators identified staffing issues as the main problem contributing to abuse within institutions and congregate housing. They stated that congregate housing is overpopulated (in part due to limited placement options) and understaffed, resulting in difficulties recognizing abuse. Abuse is also more likely to go unnoticed because staff members are underpaid, and turnover rates are high. This has become an even larger issue in the wake of COVID-19.

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, IDD Agencies, First Responders, Criminal Justice Agencies, Policymakers

Special Populations/Issues: Congregate Living, International Issues

## Awareness

The epidemic of sexual assault perpetrated against PwIDD has been a silent one sliding under the radar on both an individual and an organizational level. Fortunately, more people have become aware of the widespread problem of sexual assault and are beginning to raise awareness through public information campaigns and targeted services. In addition, tools such as The Interpersonal Violence Interview and information about recognizing and combating implicit bias has helped raise awareness about some of the underpinnings of sexual assault among PwIDD.

There is still much work to be done with regard to awareness of this problem. People must learn to recognize the signs that someone has been or is currently being assaulted or abused. While it is vital for everyone experiencing assault or abuse, recognizing the possibility of abuse is even more important for people who communicate without speech. Family and caregivers alert to the signs of abuse must act as the voice of those who cannot speak for themselves.

There is also a need for a shift in the cultural mindset that allows people to recognize and address intersectional biases. Until these intersectional biases are addressed, people will continue to face harm that comes as a result of stereotypes and overgeneralizations. And for people who have multiple intersectionalities (e.g., race, ethnicity, sexuality, gender, and disability), they face an even higher risk. This section explores opportunities to improve and expand on stakeholders' awareness of the epidemic of sexual assault among PwIDD. It also describes the persistent gaps in awareness caused by lack of education or embedded, unexamined biases.

### Opportunities

#### *Awareness-Building Campaigns*

Several developmental disability councils have implemented initiatives to build awareness and help self-advocates, family, friends, allies, and service providers to recognize, report, and stop abuse and neglect of PwIDD. Some of these programs focus on educating PwIDD and their families on healthy sexuality and relationships. Others work to better prevent, detect, and respond to sexual assault in both children and adults. For example, one group in Hawaii worked with the Department of Health's Maternal and Child Health Branch to identify groups at risk of sexual assault such as youth, immigrants, and people within the LGBTQ community (National Association of Councils on Developmental Disabilities, 2017).

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, IDD Agencies

Special Populations/Issues: LGBTQ Community, Racially- and Ethnically-Marginalized Communities

#### *Assessment and Intake Tools for PwIDD*

Disability-specific abuse is often left out of assessment tools, resulting in the erasure of the experiences of interpersonal violence for PwIDD (Atkinson & Ward, 2012). The Interpersonal Violence Interview (IVI) was developed in 2012 to try to fill this gap. The IVI's final form is a semi-

structured interview whereby PwIDD are asked questions to determine incidents of interpersonal violence over a specified period of time. Anchor points are used to specify time for the interviewee (e.g., since your birthday). Several dimensions of abuse are assessed including exploitation, sexual, physical, emotional, financial, and neglect. If a respondent answers yes to any questions, the interviewer asks additional questions to determine whether an abuse had occurred (Atkinson & Ward, 2012).

Audiences: First Responders, Service Providers, IDD Agencies, Criminal Justice Agencies

Special Populations/Issues: Domestic and Intimate Partner Violence

### *Anti-Bias Activities*

Disability is a complex experience that reflects the interaction between features of a person's body and features of the society in which they live and is now understood to be a human rights issue. People are disabled by the interactions of society—not by their bodies alone (Vera Institute of Justice, 2020a). Implicit bias is the process of unconsciously associating stereotypes or attitudes toward people, including people with disabilities. Throughout the world, people with disabilities have been secluded; have not been allowed to attend their neighborhood schools; have been subjected to aversion techniques, restraint, and inhumane treatments; and have been devalued (Vera Institute of Justice, 2020b).

Service providers, law enforcement, prosecutors, and other professionals need to better understand the experiences of people with disabilities, including the basics about different types of disability, how society's perspectives on disability have impacted the lives of people with disabilities, and legal responsibilities when serving survivors with disabilities (Vera Institute of Justice, 2020a). People whose job requires they come in contact with PwIDD should understand biases against PwIDD and confront their own biases. The first responder interviewed for this project stated that those working with PwIDD—especially medical professionals—should learn to talk less, listen more, and keep asking questions. She felt that people within a profession who are speaking out and teaching others within their profession is a critical and effective step to expanding knowledge.

The following are common myths about and biases against PwIDD:

- They are "nonverbal."
- They are not credible.
- They cannot communicate.
- They cannot explain what happened to them.
- They are a genius in specific knowledge areas.
- They need a guardian.
- They are childlike.
- They have a physical disability.
- They have an intellectual disability (Vera Institute of Justice, 2020b).

People with disabilities, particularly PwIDD, who have experienced trauma encounter additional myths including the following:

- They do not have the same response to trauma as other people.
- They cannot benefit from therapy, including trauma-based treatments.
- Behavior modification is the only option for therapeutic intervention.
- PwIDD need to tell their story to heal from trauma (Vera Institute of Justice, 2020d).

Some strategies for reducing implicit bias include:

- recognizing when you have a stereotype and thinking about why you had this thought
- thinking about people you know who do not fit into a stereotype
- focusing on what makes a person a unique individual
- imagining you are part of the stereotyped group
- spending time with people outside your group (Vera Institute of Justice, 2020b)

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, IDD Agencies, First Responders, Criminal Justice Agencies, Policymakers

Special Populations/Issues: Children With IDD, PwIDD Who Communicate Without Speech, International Issues

## Challenges

### *Failure to Recognize Signs of Abuse*

People with disabilities may experience and manifest victimization in ways that differ from those experienced by people without disabilities. This may be related to the risk factors described above. Signs may differ depending on the age of the PwIDD or their verbal abilities. It is vital for those close to PwIDD such as family, friends, caregivers, and service providers to recognize these signs of abuse as they may be vital to stopping the abuse and getting help for the survivors.

#### Importance of Recognizing Abuse

Many people lack knowledge and training about how to identify and respond to situations when disability and violence intersect. Family, friends, allies, and service providers should not mistake coercion with compassion. People with disabilities may be intimidated or forced into a situation by their abusers, and those working with and caring for PwIDD need to recognize when the level of care crosses boundaries. Disability service providers, law enforcement personnel, prosecutors, or adult protective services investigators might overlook or misinterpret signs of assault or abuse. This can lead to flawed investigations, case dismissals or closures, and survivors with disabilities who could potentially remain in the environments where the abuse occurred (Smith et al., 2017).

In the listening sessions conducted for this project, service coordinators discussed signs of sexual abuse and victimization. They suggested that it can be difficult to recognize abuse before a relationship is established with the client, but after working with someone for some time, changes in behavior and emotional response can be an indicator. One service coordinator discussed the difficulty in interpreting the source of the behavior seen in the person—not knowing whether a person is saying something because they have seen something in the media or because they have experienced it themselves. Service coordinators also indicated there is difficulty knowing what a person who communicates without speech may need.

### Verbal Signs of Abuse

People with disabilities of all ages and different communication methods may provide clues that they have been assaulted such as beginning to communicate about sexual acts. If they receive a negative reaction to this communication, they may stop, so it is vital that they have a safe, supportive environment in which they can share their communications (Vanover, 2016).

Self-advocates interviewed for this project said it might be difficult to know if someone who is not close to them were being sexually abused, stating that they might only know if someone told them outright or if they knew someone well enough to notice that something was bothering them. They stated that people can hide such experiences from those they know as they can be afraid to tell others. Self-advocates did feel they would be able to tell if someone close to them were being sexually assaulted or abused. Most indicated that they thought the person close to them would probably tell them.

### Behavioral and Physical Signs of Abuse

People who communicate without speech, especially, may leave clues in other ways, such as becoming fearful of bathing, attempting to repeat the behavior from their assault experience, or displaying their genitalia to others (Vanover, 2016). Behavioral signs of abuse can be a critical indicator of sexual assault for PwIDD who communicate without speech.

Physical signs of assault and abuse may include:

- sudden inability to meet essential physical, psychological, or social needs that may be threatening health, safety, or well-being
- disappearing from contact with people such as neighbors, friends, or family
- bruising or wounds on the skin, especially those appearing on the face or arms
- fingerprints or handprints on the face, neck, arms, or wrists
- wearing clothing that looks out of the ordinary (e.g., torn, stained, or bloody; National Adult Protective Services Association, n.d.)

Nonverbal signs of sexual abuse in children (that may also be present in teens and adults) include:

- nightmares or other sleep problems that are different from typical sleep patterns

- inability to focus
- changes in eating patterns or refusing to eat
- trouble swallowing or an unusual fear of objects near the mouth
- changes in mood that cannot be attributed to a specific cause
- new fear of specific places or people
- refusing to discuss events with others
- expression of sexual actions or images through varying media, such as drawings or acting out
- gifts, such as money or toys, that are out of the ordinary
- negative view of their body, especially the genital area (Vanover, 2016)

Nonverbal signs of sexual abuse in teens (that may also be present in adults) include:

- depression or anxiety
- abuse of drugs or alcohol
- change in hygiene
- self-injurious behaviors, such as cutting or burning
- suicidal ideation
- changes in eating habits (Vanover, 2016)

One self-advocate survivor discussed trauma as something that changes your personality and indicated that might be one way to identify trauma in another person. One self-advocate thought that behavioral changes would be an indicator in people who communicate without speech who had been assaulted. Many self-advocates stated they thought they would see behavioral changes such as withdrawal or anger in anyone they knew who had been assaulted.

### Tactics of Abusers

Abuse or assault tactics used by perpetrators might be different when used against PwIDD. It is important to recognize these potential tactics as they are also signs abuse may be taking place. Some of these tactics include:

- misuse, restricted access to, or destruction of adaptive equipment
- denial of medication or over medicating
- stalking via accessible transportation
- victim-blaming
- teasing based on disability
- forcing compliance (Vera Institute of Justice, 2020c)

### Lack of Training in the Field

Professionals interviewed for this project agreed that training on recognizing signs of abuse in PwIDD is critical but lacking in their fields. The first responder discussed the need for ongoing training and professional development but acknowledged the cost of training is a barrier for some

professionals. Similarly, service coordinators suggested that the topic of sexual assault is not discussed enough within their field, and trainings are infrequent or too costly. They recognize the urgency of this training and discussed the high rates of abuse they see in the populations that they work with. Service coordinators stated that such training, along with appropriate staffing, is necessary to recognize the signs of abuse and prevent sexual assault.

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, IDD Agencies, First Responders, Criminal Justice Agencies, Policymakers

Special Populations/Issues: People with Autism, Children With IDD, PwIDD Who Communicate Without Speech, Congregate Living, Relationships and Relationship Boundaries, International Issues

### *Intersectional Biases*

Intersectional discrimination means people are discriminated against in different, immeasurable ways based on a combination of their individual characteristics. When thinking about intersectionality, it should not be viewed as simply adding up all the ways in which a person can be discriminated against but seen as the complex blending of all these circumstances (Cramer & Plummer, 2009). Bias based on actual or perceived disability is intensified by bias based on other factors such as race, ethnicity, gender, gender identity, sexuality, immigration status, or other characteristics (Vera Institute of Justice, 2020b).

Studies indicate that traditional research with a lack of intersectional framework tends to reinforce overgeneralizations and stereotypes about people. An example is the cultural assumption that Black women are strong and resilient, which, while often is true, can lead to service providers minimizing or dismissing their attempts to seek help they may need despite their strength and resilience. In another example described by a self-advocate survivor, people may see men as only interested in sex and therefore may be less likely to believe a man can be a survivor of sexual assault or abuse. These cultural assumptions then become the basis for predictions of behavior that may be inaccurate (Cramer & Plummer, 2009).

Relevant Statistics:

- From 2009 to 2010, people with disabilities of marginalized racial and ethnic groups experienced twice the rate of violent victimization than people without disabilities (Smith et al., 2017).
- Multiracial groups had the highest rates of violent victimization (Smith et al., 2017).

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, IDD Agencies, First Responders, Criminal Justice Agencies, Policymakers

Special Populations/Issues: LGBTQ Community; Racially- and Ethnically-Marginalized Communities, Domestic and Intimate Partner Violence

## Prevention

The shocking numbers of PwIDD experiencing sexual assault clearly indicate an urgent need for prevention. Research shows that the best prevention method is comprehensive sexuality and relationship education. Fortunately, there are many opportunities for this type of education across many settings, including within families, as support for survivors of sexual assault, and at school (both in the classroom and as a part of transition planning for youth). Many programs and legislation at both the state and national level have also been implemented to support comprehensive sexuality and relationship education.

Although we know the importance of education to prevention of sexual assault, there are still many barriers to PwIDD obtaining this vital instruction. Often, instruction is oversimplified or not presented in a manner best suited to the person's ability to learn. At other times, the education is simply not available to PwIDD. Additionally, PwIDD may not have access to the informal but important education provided by families or peer models. This informational vacuum may leave PwIDD struggling to learn on their own about sexuality, and they may turn to sources that provide incorrect, misguided, or even dangerous information.

Research has also shown that some policies created to protect PwIDD from sexual assault are actually detrimental. When these policies are not consistent or not inclusive of the people implementing or utilizing the policies, they fail to work as designed. This section explores both the prevention strategies already working well and barriers that need more emphasis to become more effective at preventing sexual assault.

### Opportunities

#### *Effective and Comprehensive Sexuality and Relationship Education*

Sex and relationship education given to PwIDD is one area of sexual assault prevention that has received much attention in research. One study of such education showed gains in the areas of knowledge of healthy relationships, knowledge about abuse, safety planning skills, and safety-related self-efficacy. It also indicated booster sessions or some type of reminder system might help maintain the gains as well as possibly continue improving gains. One recommendation for future class sessions was dividing practice and learning time into multiple, shortened sessions versus compressing learning activities into a few sessions. Other recommendations included expanding the following content areas: the definition of consent and information on bullying, safety with strangers, texting and sexting, and social media and other internet safety issues. Advisors to the study recommended sexuality education be included as well (Hughes et al., 2020).

Planned Parenthood has free resources to teach youth with and without disabilities sexual health (Planned Parenthood Federation of America, 2015). There are also free or low-cost resources for people with disabilities that include visual components (Davies and Dubie, 2012; Weitlauf et al., 2013). It is important to make parents, caregivers, and service providers aware of these resources (Holmes et al., 2019).

Self-advocates interviewed for this project indicated they received varying levels of sexuality or relationship education. Some had sex education in school or other program settings. Many were self-taught using the internet or watching how others behaved. Few had open and frank discussions with family about relationships and sexuality.

The use of sexuality and relationship education as a sexual assault prevention strategy has its limitations. For example, many programs and approaches lack critical topics, are not accessible, or are not available to all people with IDD. (See *Challenge* section below which explores these issues in depth.) In addition, while education of PwIDD is an important tool, it is also critical to actively change the societal beliefs and circumstances that enable and tolerate the victimization of PwIDD (Hughes et al., 2020). In other words, it is important to focus on preventing perpetrators from victimizing PwIDD rather than encumbering PwIDD to protect themselves.

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers

Special Populations/Issues: LGBTQ Community, Transition-Age Youth, Relationships and Relationship Boundaries

### *Post-Assault Sexuality and Relationship Education*

For some PwIDD, their sexual assault is the only sexual experience they have had (Shapiro, 2018d). Many PwIDD want relationships and romance, but for people who have experienced sexual assault, it can be a barrier to obtaining those relationships (Shapiro, 2018c). It is important for them to sort through their experience and learn healthy relationships through sexuality education. One sexuality education curriculum used with PwIDD includes concrete examples, shows pictures, and uses photographs—a method that works well for PwIDD. Its creator says many PwIDD are lonely, and that loneliness can lead to entering abusive relationships. Sometimes, especially when they are young, they do not have the words to describe what happened to them as sexual assault. Comprehensive sexuality education can help address these issues by providing vocabulary and teaching about healthy relationships (Shapiro, 2018d).

The self-advocate working on the project underscored this concept. Their sexual assault made them feel like a marked person. Whether or not others were truly able to know or tell that they had been assaulted, they felt different. This caused them to struggle to initiate close relationships. In addition, they felt their assault made potential perpetrators see them as an easy target. This fear further impacted development of relationships.

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers

Special Populations/Issues: Children With IDD, Transition-Aged Youth, Relationships and Relationship Boundaries

### *Sexuality Education in Transition Planning*

Rehabilitation counselors can be an important source of sexuality education for youth with IDD while working on their transition plans. Unfortunately, this resource is largely untapped. Rehabilitation counselors may feel it is not part of their job, they are ill-equipped, or that it is the parents' job to teach about sexuality and relationships. However, rehabilitation counselors who work with secondary school staff may be positioned to coordinate this education for the youth they serve and to ensure that it is included as an important component of IEPs. It is also important for rehabilitation counselors and special education staff to learn from the youth they serve and their families what specific information and/or interventions are needed and desired (McDaniels & Fleming, 2018).

Audiences: Self-Advocates, Service Providers, Family/Friends/Allies

Special Populations/Issues: Transition-Age Youth

### *State and National Actions to Support Prevention of Sexual Assault*

On the state and national level, programs and legislation have been proposed that would work to prevent sexual assault against PwIDD. According to Shapiro (2018h), these are some of the actions attempting to prevent sexual assault.

- Massachusetts proposed a law that would create a registry of abusive caregivers, even if the case was not prosecuted. As of 2018, names of abusers were only released if prosecutors decided to take the case to trial. According to the Mass.gov website (n.d.), in 2020, the law was enacted, and names are available to those registered to view the list (typically, entities licensed to provide care).
- In the New Jersey state summit in 2018, requiring sexuality education for PwIDD in schools was proposed.
- Another proposal from the New Jersey state summit was the creation of a hotline for PwIDD to be able to report abuse and neglect, get help, and obtain support and services.
- Some states—including Pennsylvania, Minnesota, and Florida—created trainings for PwIDD to educate them about sexuality, including information about healthy relationships and how to spot abuse.
- In the United States Congress, legislation was introduced in 2018 that would guarantee the continuation of federal funding to address sexual assault of women with IDD.

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, IDD Agencies, Criminal Justice Agencies, Policymakers

Special Populations/Issues: Transition-Age Youth, Congregate Living, Reliance on Perpetrator

## Challenges

### *Barriers to Effective Sexuality Education*

As previously described, sexuality and relationship education can be a critical tool in preventing sexual assault and abuse. However, simply providing *any* sexuality or relationship education is not enough in and of itself. There are persistent issues with the structure, content, and availability of these programs that can limit their effectiveness.

#### Lack Of Equitable Access

Sexuality is part of being human; therefore, equitable access to sexuality and sexuality education should be afforded to PwIDD (McDaniels & Fleming, 2018). Yet, youth with IDD are often not given the same sexuality or relationship education as their nondisabled peers. Some researchers suggested closing this gap by ensuring that sexuality education is an integral part of transition planning and thus a student's IEP (McDaniels & Fleming, 2018).

Service coordinators interviewed for this project affirmed that sexuality education is highly important in the prevention of sexual assault, but that they rarely see adults with IDD receiving this education. Despite some service providers and parents believing that PwIDD do not have a complete understanding, several service coordinators emphasized the need to be honest with PwIDD about their bodies and appropriate relationships. The relationship among service coordinator, parent or guardian, and client was a source of frustration in this regard, and service coordinators often felt they were not empowered to provide this kind of information or education.

Self-advocates interviewed had a wide variety of access to sexuality and relationship education. This appeared to trend along age lines. For example, the oldest participants (in their 60s and 70s) had received no sexuality education. As age decreased, the amount and quality of sexuality education seemed to increase. (Though, with so few participants we cannot draw definitive conclusions.)

#### Oversimplification of Sexuality Education

Many sexuality education programs designed specifically for PwIDD are too simplistic. For example, programs may use the constructs of good touch/bad touch or stranger danger. However, people who sexually assault PwIDD are usually not strangers to the survivors. Therefore, these constructs may, at best, fail to prepare PwIDD to recognize potential abusers and, at worst, make it easier for abusers to groom and eventually assault their victims (Shapiro, 2018d).

In addition, critical topics may be left out of sexuality education given to PwIDD, and these gaps can be dangerous. For example, one source indicated that some parents of girls with autism taught about privacy, identifying sexually abusive behavior, hygiene, and menstruation but did not address the healthy aspects of sexuality. Parents of girls with autism with lower cognitive functioning often did not teach about relationship topics like dating and marriage, knowing when one is in love, and how to decide when the right time is to engage in sexual intimacy with a partner. Parents of girls with higher cognitive functioning covered the consequences of getting pregnant and reasons why teens should abstain from sex, but few covered preventing unintended pregnancy and sexually transmitted infections (Holmes et al., 2019). Similarly, one program found that HCBS waiver services

dealing with sexuality tended to focus on preventing unwanted sexual behaviors and not on educating about appropriate sexuality (McDaniels & Fleming, 2018).

Topics recommended by various research studies and programs include:

- relationships: friendship, dating, and marriage
- relationship boundaries
- knowing when one is in love
- deciding when to engage in sexual intimacy with a partner
- consent
- consequences of getting pregnant
- preventing unintended pregnancy
- preventing STIs
- body awareness and love
- hygiene
- gender identity
- social acceptance
- privacy
- identifying sexually abusive behavior

The self-advocates interviewed for this project agreed that more information is better. Some self-advocates discussed that an important part of sexuality education should specifically address sexual assault and abuse. They felt important topics might include knowing how to defend oneself, knowing how to get out of dangerous situations, and knowing where to go for help.

### Inaccessibility of Sexuality Education

Providers of sexuality education—whether parents and families, educators, or even service providers—must ensure that the content is accessible. It must be provided in a way that PwIDD can understand and internalize. Effective sexuality education curricula tend to be individualized, concrete, diverse in teaching method, and featuring opportunities for practice and reinforcement over time (McDaniels & Fleming, 2018).

Often, however, the teaching methods used are limited or do not match the learner’s needs. For example, one study reported that most parents only used verbal discussion when teaching sexual education. Another study found that the number of parents who used visual aids (e.g., pictures, books, videos) to assist in education was low, and the number of parents who used skill-based methods (e.g., role playing, social stories) was even lower. Parents who did use visual and skill-based methods said that access to resources, knowledge of techniques, and time needed to find or create visuals may prevent other parents from using these methods (Holmes et al., 2019).

### Lack of Peer Models

As youth age, they begin to get most of their information about and understanding of sexuality from peers. PwIDD who are often isolated from peers without disabilities are consequently also isolated from this information or understanding. The challenge becomes especially acute as youth transition to adulthood and relationships become deeper and more nuanced (e.g., levels of friendship are overlaid with romantic associations). This lack of knowledge can lead to mild challenges, such as missing social cues, but also to more extreme challenges, such as the inability to maintain relationships and difficulties navigating the workplace (McDaniels & Fleming, 2018).

### Parental/Familial Challenges

Sexuality education for PwIDD can be incomplete or ineffective based on parental or familial issues and challenges. For example, parents may not provide education if their child does not proactively express an interest. However, some PwIDD (one study focused on individuals with autism) may not share their interests with others, may have less access to cultural or peer information about sexuality, and may process emotions differently. These factors may contribute to their not expressing an interest in sexuality—even when they may, in fact, be interested. In addition, people who are asexual often are interested in relationships, so teaching about healthy relationships is always important. Finally, whether youth decide to engage in sexual relationships or not, learning about sexuality and relationships helps them learn how to relate better with others and increases autonomy and self-advocacy skills (Holmes et al., 2019).

Fear can also play a part in parents failing to address sexuality with their children. Some parents may simply fear they are not equipped to have conversations about sexuality (Holmes et al., 2019). Parents of PwIDD may also be reluctant to talk with their children about sex because they fear it will lead them to being sexually active and open them up to sexual assault. Service provider listening session participants affirmed this, indicating that sometimes parents bar them from providing sexuality education or speaking frankly about sexuality. Many educators say—and research shows—that the opposite is true. Comprehensive sex education is the best way to prevent sexual assault (Shapiro, 2018d).

Although some self-advocates interviewed for this project received sex education at home, they stated that they feel it is unusual to receive such information from parents. Some self-advocates who did not receive sexuality education at home thought perhaps they had not received it because it felt too personal or that their parents did not know how to educate their children on sexuality. Self-advocates emphasized the importance of parents educating their children about sexuality and allowing their children to have relationships. The self-advocate working on this project agreed, indicating that when parents try to “keep their children under a dome” of protection, they are really putting them more at risk.

### Use of Pornography and Internet

Often, when denied sexuality and relationship education, PwIDD turn to other sources for information. Social media and the internet were cited in the research as sources for both

information about sexuality and for finding partners (McDaniels & Fleming, 2018). Participants in the self-advocate and service coordinator listening sessions also mentioned the internet as a potential source.

The self-advocate working on this project also noted that it is so easy to find pornography on the internet, it makes people think the behavior shown is okay. This use of pornography can be extremely harmful and open PwIDD up to be both survivor and perpetrator. For example, a member of the research team working in criminal justice initiatives described a self-advocate who turned to pornography to learn about sex and unintentionally encountered child pornography. Not understanding the boundary between acceptable and illegal pornography, that individual ended up on the sex offender registry. Service coordinators participating in the listening sessions also felt pornography use was prevalent and could easily spiral out of control. One service coordinator described a client who had become so addicted to pornography that they could not maintain a job.

Another service coordinator described a young woman with IDD seeking a relationship online. She did not understand the dangers of doing so, and the service coordinator was not able to prohibit her from doing so because her guardian said she was an adult and should be allowed to do what she wanted. They feared the woman's behavior was risky but felt that their hands were tied from intervening. They felt that educating parents and guardians about the dangers of such activities and the importance of sexuality education would be beneficial.

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers

Special Populations/Issues: LGBTQ Community, People with Autism, Transition-Age Youth, Relationships and Relationship Boundaries

### *Lack of Inclusive and Consistent Policy*

One study found a lack of explicit policies aimed at protecting PwIDD from sexual assault and abuse that are inclusive and implemented across stakeholder groups. Data gathered from a survey indicated that senior service managers and direct care staff had the highest levels of direct participation in policy development with comparatively low participation from service users (PwIDD), family, care staff, and other local service providers. In addition, the definition of abuse varied by agency, and this variation contributed to less consistent implementation of policies and less protection for the service users. Some stakeholders felt that many people knew policies existed but did not understand their content. Many expressed that policies' impacts were not evaluated, leading to duplicative or ineffective policies. The study recommended that future development of policies aimed at protecting PwIDD from sexual assault or abuse focus more closely on inclusivity, consistency, clarity, and evaluation of impact (Northway et al., 2007).

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, IDD Agencies, Criminal Justice Agencies, Policymakers

## Reporting

Assaults against people with disabilities are underreported. The National Crime Victim Survey (NCVS) found that between 2010 to 2014, 47% of violent crimes against people with disabilities were reported to police. Other research shows that might be much lower. For example, one study of college students with disabilities showed that only 27% reported (Smith et al., 2017). In another recent study, only 37.3% of adults with disabilities said they reported their abuse to authorities. In this study, reports by PwIDD and their families increased the reporting rate to 51.7%. This suggests that when a family member learns of assault or abuse, it becomes more likely that a report will be filed (Vera Institute of Justice, 2020c).

Of note, there were comparatively few opportunities for improved reporting outcomes described in the research and therefore explored in this section. Here, we focus on the pervasive, systemic challenges that prevent PwIDD and those who support them from reporting potential sexual assault and abuse. These challenges include fears and misconceptions held by PwIDD about reporting, bias on the part of those to whom reports are made, and systemic obstacles to effective reporting.

## Opportunities

### *Autonomy and Choice for Survivors*

Any agency helping survivors should emphasize survivor empowerment in addition to incorporating cultural contexts. For example, research on criminal justice responses to domestic violence indicates that survivors of domestic violence express increased satisfaction when they experience support, sympathy, and encouragement from officers, prosecutors, and judges. Additionally, several studies have shown that survivors desire support, a sense of control, and a voice in how the criminal course of action will proceed. Survivors feel empowered when they become involved in their proceedings, such as through victim impact statements used to inform sentencing decisions (Cramer & Plummer, 2009).

The self-advocate working on this project also emphasized the importance of personal choice in reporting and telling one's story. They emphasized that people will always have an opinion about whether, when, and how a survivor should report. The important thing is that the survivor keeps control of their own story.

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, IDD Agencies, First Responders, Criminal Justice Agencies

Special Populations/Issues: LGBTQ Community, Racially- and Ethnically-Marginalized Communities, Children With IDD, Congregate Living, Domestic and Intimate Partner Violence

### *Legal Protections for PwIDD (ADA Title II)*

Title II of the Americans with Disabilities Act (ADA) prohibits discrimination against people with disabilities in state and local government services, programs, and employment. This includes law enforcement agencies. This protection means when a PwIDD is assaulted and they report the crime,

the responding officers must carry out their duties in the same way they would for a person without disabilities, including taking complaints, interviewing witnesses, and providing emergency medical services (Vera Institute of Justice, 2020c).

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, First Responders, Criminal Justice Agencies

## Challenges

### *Not Knowing How to Report*

The self-advocate working on this project emphasized that many self-advocates do not know where or how to report sexual assault or abuse (i.e., when to use Texas Health & Human Services' 211 hotline, when to call Adult Protective Services [APS], etc.). When discussing how to report, self-advocates interviewed for this project demonstrated some knowledge of reporting protocol by stating that they knew they would need to call the police, a hotline, or APS. One self-advocate expressed not knowing what happens following reporting, while another believed the incident would be investigated to build a case against the perpetrator.

Self-advocates in congregate housing shared that their homes had varying levels of information about sexual assault and abuse reporting. One self-advocate reported that their group home had a phone number posted in common areas so residents could call to report abuse. Other self-advocates stated there were no written reporting guidelines in their group home but believed they would be helpful.

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers

Special Populations/Issues: Congregate Living

### *Stigma*

Stigma is another powerful force that keeps PwIDD from reporting sexual assault and abuse. Some survivors describe that they were afraid to report their assaults because they were worried they would look bad to others (Shapiro, 2018g). Stigma can also be cultural, as some cultures promote the belief that family matters should not be made public and informing outsiders would bring embarrassment to the family and their culture (Cramer & Plummer, 2009). The self-advocate working on this project affirmed this, describing family members not wanting them to report because they were embarrassed and did not want others (friends, neighbors, coworkers) to know what happened. However, they also indicated that it was a growing experience for them to report their sexual assault because it helped them overcome fear of what others would think.

Several participants in the listening sessions indicated that bias and fear reinforce stigma, which in turn reinforces the silence surrounding this issue. The first responder indicated that in their field, people are doubly uncomfortable talking about sexuality and sexual violence in general and that perpetrated against PwIDD specifically. Service providers indicated that sometimes, parental fears of

sexual violence against their children led parents to shy away from frank discussions of sexuality. Conversely, the service providers felt that too little knowledge about appropriate sexuality is more likely to endanger their clients than protect them. Finally, self-advocates living in congregate housing felt that people might be afraid to report sexual assault and abuse because of what others in the living arrangement might think or say.

Audiences: Self-Advocates, Families/Friends/Allies, Service Providers, First Responders

Special Populations/Issues: LGBTQ Community, Racially- and Ethnically-Marginalized Communities, Children With IDD, Congregate Living, Reliance on Perpetrator

### *Mistrust and Fear of Law Enforcement*

According to Shapiro (2018e), NPR reports based on numbers obtained from the Justice Department household survey indicate 40% of PwIDD, their family members, or caregivers did not report sexual assault because they believed police would not or could not help them. Thirty seven percent of PwIDD stated that they handled the assault another way instead of reporting. Of those who did not report, 13% of women with IDD said they did not report because they believed police would not help. People of color with disabilities who are survivors of abuse have also voiced their fears of differential and prejudicial treatment by law enforcement personnel (Cramer & Plummer, 2009).

Self-advocates interviewed for this project expressed fear regarding discussions with the police. One person discussed their anxiety levels rising at the thought of speaking with the police and another expressed fear of being handcuffed or arrested. Another self-advocate stated that speaking with the police makes them nervous, and they worry that they may have a panic attack. A general fear of being in trouble with the law resonated throughout the self-advocate groups.

The self-advocate working on this project indicated that training for police officers on how to be more accessible to PwIDD should occur, and it should emphasize “being the person you are when you’re not wearing the uniform.” Another self-advocate survivor said that when they reported their abuse, the police officer who interviewed them spoke fast and asked questions quickly without making eye contact. The survivor expressed the need for eye contact, plain language that is easy to understand, and a slower discussion that helps the survivor feel comfortable and gives them time to gather their thoughts. Another self-advocate expressed how their nurse advocated for them and helped the officers speak to them in a way that felt comfortable, and that made a difference.

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, First Responders, Criminal Justice Agencies

Special Populations/Issues: Racially- and Ethnically-Marginalized Communities

### *Fear of Negative Consequences*

For many people, regardless of disability, the process of reporting a crime can be fraught with fear. For PwIDD, these fears are often magnified because of how they may be (and have historically been)

perceived. In addition, PwIDD who rely on individuals, organizations, and systems for support in daily living may fear loss of these supports. Several self-advocate survivors interviewed for this project affirmed that much of the abuse they have experienced was not reported due to fear. They feel that survivors need to know the assault and perpetrator were bad, not the person talking about the assault. Fears described by self-advocates and others interviewed for this project, and by the research, include the following information in the sections below.

### Fear of Retaliation

Fear of retaliation is a powerful silencing factor. According to NPR reports based on numbers obtained from the United States Justice Department household survey, 20% of PwIDD or their family members or caregivers did not report sexual assault because they feared retaliation (Shapiro, 2018e). The self-advocate working on this project also shared that sometimes PwIDD are afraid to report sexual assault, abuse, or harassment at day habilitation facilities, congregate living situations, or other formal settings because they might be put on a behavior plan instead of getting help.

### Fear of Loss of Independence

One study indicated people with disabilities did not report because of their fear they would lose their independence or be put in an institution (Smith et al., 2017). The self-advocate working on this project also mentioned that placement challenges are common for PwIDD. Some people might be concerned that they would have to give up their placement by reporting someone who is their caregiver or another resident.

### Fear of Loss of Support

Survivors may be reluctant to turn to the police and courts because they depend on the abuser for financial support, assistance with children, housing, and transportation. Those with disabilities may rely on their abusive partners to help with daily living activities, such as toileting, bathing, and eating (Cramer & Plummer, 2009).

### Fear of Not Being Believed

PwIDD are often not thought to be credible when reporting sexual assault (Shapiro, 2018a; Vanover, 2016). Many PwIDD who have been sexually assaulted describe reporting their assault and not being believed. They sometimes had to report the assault multiple times before they were believed. Sometimes they were told they asked for the assault (Shapiro, 2018g).

The self-advocate working on this project indicated that many survivors may not report, even to family members, for fear of not being believed, although advocacy can help people overcome this fear and their past negative experiences. One self-advocate survivor interviewed for this project described that after they told their service coordinator about the rape they experienced, the service coordinator did not report the assault and did not contact APS. The survivor did not get the opportunity to speak to APS, expressing feelings of frustration and betrayal over this experience. Another survivor stated that they worried people would not believe them, and they felt scared

because of that. Another survivor reinforced this idea by reporting that their mother did not believe them. They stated this treatment of people with disabilities leads them to not telling the full truth, and their difficulty in expressing their feelings makes the process of reporting even more challenging.

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, IDD Agencies, First Responders, Criminal Justice Agencies

Special Populations/Issues: Racially- and Ethnically-Marginalized Communities, Congregate Living, Reliance on Perpetrator, Domestic and Intimate Partner Violence, Relationships and Relationship Boundaries

### *Law Enforcement and Agency Bias*

There is often a bias against PwIDD, especially if they speak slowly or have a vocabulary below what is expected of their age. This bias causes people to see them as simpleminded, worthless, or that they must have been complicit in the assault. They are seen as people without feelings or life experience (Shapiro, 2018f). Often, police are not trained to recognize this bias in themselves. Bias based on actual or perceived disability may be further intensified by bias based on race, ethnicity, gender, gender identity, immigration status, sexuality, or other characteristics (Cramer & Plummer, 2009; Vera Institute of Justice, 2020b). Finally, sexual assault that occurs between people with disabilities is often not treated as a crime by those who work with people with disabilities because they are not familiar with the laws surrounding sexual assault (Pennsylvania Coalition Against Rape, n.d.).

Audiences: Self-Advocates, Family/Friends/Allies, First Responders, Criminal Justice Agencies

Special Populations/Issues: LGBTQ Community, Racially- and Ethnically-Marginalized Communities, PwIDD Who Communicate Without Speech, Domestic and Intimate Partner Violence

### *Institutional Silence*

In congregate settings unreported abuse may be as high as 85% (National Association of Councils on Developmental Disabilities, 2017). One study of policy implementation between multiple agencies indicated that overall, abuse was being identified and that allegations of abuse were being followed up. However, the police were less likely to be involved when abuse occurred in a congregate setting, and there were variations in how the policy was implemented by different social services teams. Developmental disability teams were more likely to follow the policy. However, it was also noted that good working relationships between agencies were variable, and staff turnover could influence these relationships and thus reporting outcomes (Northway et al., 2007).

Reporting to law enforcement may also be delayed in congregate settings because of the process of filing the report. For example, a survivor of sexual assault who lives in a group home may report to staff right away, but an internal investigation may be conducted before a report is made to authorities. Additional delays can occur when the offender is a provider of needed services, and a

replacement to fill those services must be in place before the crime is reported. This delay in reporting could mean that the offender is not held accountable, the survivors remain at risk, and there is potential for other people to be at risk (Vera Institute of Justice, 2020c).

Abuse in congregate settings can be ongoing and systemic. For example, a supervisor at the Rainier School in Washington was caught in the act of sexually assaulting a woman with IDD who lived at the state institution. Investigators discovered the supervisor had multiple allegations of sexual assault over 10 of the 20 years he worked at the same cottage at the institution. Washington state's oversight agency faulted the Rainier School for failing to protect residents. They claimed administrators knew there was abuse and did not prevent more abuse by reporting the supervisor. Administrators also did not train staff to recognize abuse or provide therapy or support to those who were assaulted (Shapiro, 2018b).

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, IDD Agencies, First Responders, Criminal Justice Agencies, Policymakers

Special Populations/Issues: Congregate Living

### *Mandatory Reporting and Adult Protective Services*

In most states, life-threatening situations involving an adult with disabilities must be reported to APS (or a similar agency) immediately, which then investigates when the signs of abuse are observed or suspected (National Adult Protective Services Association, n.d.). Yet, there are critical challenges associated with mandatory reporting.

The first responder interviewed for this project described this duality, saying that reporting can be part of the healing process, but can also lead to further traumatization. They described the power that can come from a person's choice to disclose their sexual assault (or not) and how that power can be taken from a person through mandated reporting. At the same time, as with all people, PwIDD may sometimes have difficulty judging how best to take care of themselves after trauma, and this is one situation where mandatory reporting is necessary, especially for those who cannot appreciate the long-term consequences of what happened to them. In their mind, the positives often outweigh the negatives of mandatory reporting, but not all first responders feel this way. The key challenges associated with mandatory reporting are lack of system capacity and loss of survivor control.

#### Lack of System Capacity

First and foremost, APS agencies are typically overwhelmed and understaffed, resulting in epidemic failures in follow-up of potential abuse. For example, a 2018 news article indicated that in Texas:

- More than 100,000 callers per year to the Texas Department of Family and Protective Services (DFPS) Abuse Hotline (which includes both child and adult protective service calls) hang up before reaching an operator because of long hold times.

- DFPS was on track to have 180,000 abandoned abuse-line calls in 2018.
- There had been 23 days in 2018 in which a caller had been on hold for more than an hour (versus one or two days in past years; Chang, 2018).

Also in 2018, a Texas state auditor found that APS caseworkers failed to make regular contact with clients to ensure their safety. Agency staff pointed to very high staff turnover (24% each year) as the reason for these issues (Asher, 2018). This increases the likelihood that reported assault and abuse will go unpunished and decreases the likelihood that survivors will have access to needed supports.

Service coordinators interviewed for this project expressed great frustration with long hold times and questions that were difficult to answer when exploring a potential report with APS staff. One service coordinator also discussed their experience with agencies not acting on the reports or giving too much leeway due to the adult age of the survivor. Another service coordinator expressed frustration when reports to APS did not lead to investigations.

#### Loss of Survivor Control

A mandatory report also has the potential to remove a survivor's control over their experience, and it might lead to an investigation that re-traumatizes the survivor. On the other hand, reporting might be empowering for a survivor if they can participate meaningfully in the reporting process (Vera Institute of Justice, 2020d). The self-advocate working on this project also indicated that mandatory reporting issues can contribute to survivors' fears about what will happen if they report. For example, mandatory reporting triggers an investigation. This means many people in the survivor's life will know what happened, increasing stigma. And if the case is dismissed or not pursued, the survivor may feel endangered by the perpetrator knowing their crime was reported.

If a person with a disability appears to be disclosing assault or abuse to a service provider, the service provider should explain any mandatory reporting requirements before the person discloses. They should also explore the option of referring the person to an anti-violence agency. If such a referral is made, the service provider must take responsibility for the quality of the referral by supporting the person through the referral process and staying connected to make sure the referral meets their specific needs (Vera Institute of Justice, 2020d).

In addition, when disclosing an assault or abuse, a survivor might prefer to speak with a familiar, trusted person rather than a stranger. If a survivor discloses and a mandatory report must be filed, the focus must first be on the survivor and their safety as well as their need to heal. After the report is filed, the survivor will need support through any investigations that might result from the report as well as follow-up at regular intervals (Vera Institute of Justice, 2020d). Many of the self-advocates interviewed for this project agreed, stating they would first tell someone that they trusted and then call the police. They also expressed some comfort in reporting if someone they trust could support them in that process.

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, IDD Agencies, First Responders, Criminal Justice Agencies, Policymakers

## First Response

After a sexual assault has occurred, a survivor's interactions with first responders (EMTs, police officers, emergency room staff, etc.) are critical to positive adjudication and trauma recovery outcomes. For this reason, we have addressed First Response as separate from Adjudication or Survivor Support, although there is significant overlap in personnel and issues across these domains.

Critical early investigative efforts can make or break a sexual assault case. Interactions at this stage must optimize evidence collection, which can sometimes be challenging due to investigators' implicit biases against PwIDD. When these biases meet PwIDD's learned compliance and communication challenges, effective evidence collection can be further compromised. In addition, as described by the first responder interviewed for this project, time constraints in the emergency room make thorough examinations difficult. Medical professionals in the ER must admit the patient, gather evidence, treat the patient, and release within a few hours. Some feel it is faster not to engage the patient in too many questions. However, this practice could leave important evidence behind. A self-advocate survivor interviewed for this project affirmed that they wished they had more evidence when they reported, suggesting a need for support with evidence collection.

Similarly, biases held by first responders can impact the quality and timeliness of support provided to survivors and can even re-traumatize survivors. The first responder interviewed for this project expressed how harmful first responders and law enforcement can be when they are not trained as advocates to PwIDD, adding that "no one can mandate compassion."

Yet, some organizations are working toward more inclusive and accessible evidence-gathering techniques that can lead to more positive adjudication outcomes. Approaches that are trauma informed, person-centered, and accessible can lead to better support services and improved recovery. This section describes the formal and informal approaches, strategies, and tools that can optimize first response. It also describes the significant challenges that can render first response ineffective in gathering needed evidence and can re-traumatize survivors.

## Opportunities

### *Understanding Barriers to Reporting*

The *Reporting* section of this framework describes the significant barriers—both internal and external—PwIDD face in reporting sexual assault or abuse. Barriers are more than just physical obstacles, and often, more than one barrier occurs at a time. Barriers can be unintentionally created by first responders (e.g., implicit bias), by the survivor (e.g., fear of consequences), or even by those who are supposed to be supporting the survivor (e.g., stigma and institutional silence). First responders who are trained to understand and recognize these barriers can better respond to and support PwIDD (Vera Institute of Justice, 2020b).

Audiences: First Responders, Criminal Justice Agencies

Special Populations/Issues: LGBTQ Community, Racially- and Ethnically-Marginalized Communities, Congregate Living, Reliance on Perpetrator

### *Empathy and Trust*

One of the greatest needs of anyone who has experienced trauma is the need to feel safe. Trust is central to meeting that need. Demonstrating genuine empathy and understanding to a survivor can help provide a safe environment that is open and nonjudgmental, which leads to more trust. Acknowledging the ordeal that the survivor has endured shows understanding and also cultivates trust. Believing the survivor is also critical (Shapiro, 2018g; Vera Institute of Justice, 2020b).

This is especially important during initial contact with the survivor of crime with a disability as it may impact the entire course of the investigation. The first interview needs to be conducted with compassion and empathy or the case may be damaged beyond repair by the loss of the survivor's trust and rapport (Vera Institute of Justice, 2020c).

The self-advocate working on this project used a movie analogy to explain how important empathy and trust building was in their situation. They told the ER nurse calling for police that they needed a person who was gentle and not threatening—"Not a 'Dirty Harry' type and no weapons." The first responder participating in the listening sessions also felt that empathy and trust were paramount to effectively helping PwIDD who are survivors of sexual assault. They expressed the importance of believing the survivor and how this act of compassion can help evoke trust. They stated that people must be willing to ask tough questions and be open to hearing the tough answers.

Audiences: Self-Advocates, Families/Friends/Allies, Service Providers, IDD Agencies, First Responders, Criminal Justice Agencies

### *Trauma-Informed Care*

The first responder interviewed for this project discussed their own journey to working with sexual assault survivors, which included Trauma-Informed Care training. A trauma-informed responder must be sensitive to the potential impact that trauma can have on people with disabilities. They should also understand that the procedures and interactions they use may be re-traumatizing. A trauma-informed approach includes these principles:

- safety
- trustworthiness and transparency
- peer support
- collaboration and mutuality
- empowerment
- voice
- choice

Yet, the first responder described quality of care that is often provided to PwIDD at this stage as poor. They stated that first responders have little tolerance for compassion in general, which is compounded when they work with PwIDD due to their discomfort with the population. Service coordinators also discussed the lack of Trauma-Informed Care training in their field, stating that trainings are often inaccessible or expensive.

Audiences: Service Providers, First Responders, Criminal Justice Agencies

Special Populations/Issues: Congregate Living

### *Person-Centered First Response*

First responders who put the person first and emphasize perspective taking are helpful for PwIDD who report abuse (Shapiro, 2018g). This response may include or address:

- meeting communication needs (e.g., asking the survivor what they need and knowing alternate ways to communicate)
- removing physical barriers (e.g., being able to transport people with disabilities easily, providing services in a way that does not put the person at physical risk)
- providing accessible information (e.g., giving information and instructions in plain language and using videos, podcasts, or other accessible tools)
- meeting the person in their social world (e.g., focusing on the safety and independence of the person)
- taking into consideration important aspects of a person's identity, such as culture, history, and gender (Vera Institute of Justice, 2020b)

Police officers responding to a sexual assault or abuse call involving a survivor with IDD should also be aware of the various types of physical and mental impairments covered under the Americans with Disabilities Act. Often, these impairments can inhibit a person's ability to hear, see, understand, or respond to an officer, leaving them unable to respond to questions, directions, or orders given by that officer (Vera Institute of Justice, 2020b). Similarly, an emergency operator taking information from a survivor with a disability should learn as much as possible about the person's disability. This information can help responding officers prepare for their approach, response strategy, and any accommodations that may be needed (Vera Institute of Justice, 2020c).

The self-advocate working on this project describes how the Sexual Assault Nurse Examiner (SANE) who worked with them went at their pace and how that made the examination easier for them. Similarly, the first responder participating in the listening sessions said providing necessary accommodations to PwIDD (such as writing when someone communicates without speech) and meeting the person where they are by valuing their needs and emotions can provide greater insight into someone's experience.

Audiences: Self-Advocates, Families/Friends/Allies, Service Providers, First Responders, Criminal Justice Agencies

Special Populations/Issues: LGBTQ Community, Racially- and Ethnically-Marginalized Communities, PwIDD Who Communicate Without Speech, Reliance on Perpetrator

### *Ready Support and Service Referrals*

When first responders conclude the initial interview, they should ensure the following are provided to survivors immediately:

- referrals to local victims' services
- options for alternative living situations if the current situation is not safe
- alternate caregiver if the current caregiver is arrested
- the interviewer's contact information
- an overview of what they can expect to happen next (Vera Institute of Justice, 2020c)

Connecting survivors of sexual assault to a rape crisis center can help them access needed services including crisis intervention, hospital accompaniment, support groups, counseling and therapy sessions, victim advocacy, and victim compensation. After the initial interview is conducted, it is critical that investigators stay in touch with the survivor throughout the course of the investigation. Even if nothing is happening on the case or the case is being closed, survivors need to know this to help them achieve closure in their lives (Vera Institute of Justice, 2020c). The self-advocate working on this project noted that there was no checklist for what kind of help to get after their assault. Their local chapter of The Arc provided some information, but there was no central place with accessible information on how to get help.

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, First Responders

Special Populations/Issues: Reliance on Perpetrator, Domestic and Intimate Partner Violence

### *Effective Interviews*

Effective interviews of survivors of sexual assault and abuse who have IDD are critical for a number of reasons. First and foremost, interviews that are performed by trained personnel in a location that is designed for the needs of PwIDD are less likely to re-traumatize the survivor. In addition, lack of evidence and implicit bias during the adjudication period severely limit the number of cases successfully prosecuted. These interviews are critical in establishing solid and usable evidence that leads to successful adjudication. Literature reviewed emphasizes key points in the interview process as describe below.

#### Setting

The setting in which interviews with PwIDD are conducted is important to establishing rapport and helping the survivor feel comfortable and relaxed, which in turn increases the quality of evidence gathered. Specialized settings for adults with IDD are typically not available. However, sometimes settings designed for children are used and may offer insight into the way setting can be effectively

designed. For example, a child advocacy center in Newark, New Jersey, uses the following design to lessen stress on children following abuse.

- The first floor of the building is designed for interviews with the children and is decorated invitingly.
- The rooms where interviews take place with trained counselors are adjacent to other rooms where law enforcement, prosecutors, and others can observe the interview and ask questions remotely. This allows for fewer interviews with the survivor since all parties are there together.
- On the second floor of the building, police and prosecutors have offices from which they work the cases, but they are out of sight of those being interviewed. Such environments can minimize survivor trauma by enabling all staff interacting with the survivor to come to a single place rather than having the survivor go to multiple locations.
- Health care professionals (including therapists and a nurse who can perform a rape kit examination), police, and prosecutors work collaboratively in one location.

This building and those working in it have also been used for PwIDD, as has the technique of streamlining interviews. In these cases, streamlined interviews were held in a room designed for adults rather than children (Shapiro, 2018e).

### Initial interview

Establishing trust and building rapport are critical when working with survivors of sexual assault. This typically occurs in the initial interview. Effective interviewing strategies may include:

- giving the survivor power during introductions by asking, for example, “May I come in?” or “May I sit here?” (Vera Institute of Justice, 2020c)
- explaining to the survivor why they need to do the interview and what will happen throughout the entire process (Vera Institute of Justice, 2020c)
- letting the survivor know that some questions may ask for a lot of detail, might seem intrusive, and have no right or wrong answers (Vera Institute of Justice, 2020c)
- asking concrete and literal questions (Shapiro, 2018e)
- checking the survivor’s understanding of what was said by having them repeat it in their own words (Vera Institute of Justice, 2020c)
- watching for the survivor's verbal and nonverbal cues such as closed off posture, lack of eye contact, or change in voice when a specific topic or question arises (Vera Institute of Justice, 2020c)
- watching for tension and discomfort, shifting to other questions as indicated, and then returning to difficult topics once the survivor seems more relaxed (Vera Institute of Justice, 2020c)
- watching for learned compliance and probing more deeply when needed (Vera Institute of Justice, 2020c)

- using a collaborative approach to lessen the trauma on the survivor while better preparing for prosecuting the perpetrator (Shapiro, 2018e)

If trust and rapport cannot be established with the survivor, the officer should bring in a victim advocate for support. Additionally, they should allow the victim advocate to speak with the survivor privately (Vera Institute of Justice, 2020c).

### Forensic Interviews

According to Vera Institute of Justice (2020c), the goals of a forensic interview are to minimize any potential trauma to the survivor, maximize information obtained from the survivor and witnesses, reduce contamination of the survivor's memory event, and maintain the integrity of the investigative process. The effectiveness of using forensic interviewing with children is well established, but there is little to no research of using this style of interview with adults. Nonetheless, there is a trend of using it with adults with disabilities.

Vera Institute of Justice goes on to explain that forensic interviews for adults usually only occur in cases in which an adult is considered vulnerable (i.e., are not able to take care of themselves). However, this makes a dangerous assumption that what works for a child will work for an adult with a disability and sets a risky precedent for interviewing adults with disabilities. The assumption that a person trained to work with children can easily adapt their experience to work with adults with disabilities ignores the life experiences that an adult with a disability brings into their interview.

However, forensic interviewers are trained to be trauma-informed and are likely better positioned to interview people in a nonthreatening, non-traumatic way while ensuring the information they gather will hold up in court. This style of interviewing could be beneficial for adults with disabilities. Vera Institute of Justice states there should be standardized training on the adult forensic interview model rather than depending on the format used with children.

The self-advocate working on this project indicated that another important factor in their forensic interview was choosing the right support person. The person who supported them did not speak for them and stepped away when it was time for the physical exam. They felt this was integral to the effectiveness of the forensic interview and in minimizing the trauma they felt.

### Follow-Up Interviews

One of the most important components of an investigation is a detailed follow-up interview conducted with the survivor, which should be held a day or two after the assault was reported. For certain types of crimes, (e.g., sexual assault, domestic violence, and human trafficking) it is essential that the follow-up interview is conducted using a trauma-informed approach. The interview should be scheduled considering the survivor's needs for time and place, and the interview should be conducted as soon as possible to prevent memory loss on the part of the survivor. This also protects the survivor from any potential claim that someone improperly influenced the survivor's statement (Vera Institute of Justice, 2020c). The self-advocate working on this project emphasized that in their case, the officer that conducted the follow-up interview was trained in interviewing for sexual

assault. He took one thing at a time and did not rush. They feel it is critical to work at the survivor's pace, not the interviewer's pace.

Best Practices for Interviewing Children

Generally, one comprehensive forensic interview is all that is needed for children. However, children with disabilities may need multiple interviews to allow them to share their information at a comfortable pace. This may lead to interviews that are longer, require more breaks, and require adjustments due to fatigue. Interviewers should also consider the location of the interview. It should be conducted at a neutral, non-isolated place (e.g., police station or family justice center). Interviewers should also engage in narrative practice—asking the child about a neutral or positive event that prepares them for the actual interview (Vera Institute of Justice 2020c).

Vera Institute of Justice (2020c) suggests when interviewing children with IDD, the interviewer should also be prepared to:

- repeat what they say orally or in writing
- limit distractions prior to the interview and provide a private space for pre-interview questions
- be patient, flexible, and supportive—making sure they understand the child, and the child understands them
- help with forms or understanding written instructions without over-assisting or patronizing the child

Additionally, Vera Institute of Justice suggests potential interview tools helpful for children include allowing the child to draw and using maps and anatomically detailed body drawings. These tools are useful in eliciting more details, grounding the child to specific events, helping demonstrate an action or position, organizing the child's narrative, and alleviating anxiety.

Audiences: Self-Advocates, Family/Friends/Allies, First Responders, Criminal Justice Agencies

Special Populations/Issues: Children With IDD, PwIDD Who Communicate Without Speech

## Challenges

### *Implicit Bias*

As described in the *Reporting* section, implicit bias is the unconscious association of stereotypes or attitudes toward people. As with every aspect of sexual assault prevention and response for PwIDD, implicit bias in first responders must be acknowledged and addressed to improve outcomes for the survivor. Sometimes the urgency of a situation requires first responders, in particular, to make quick decisions that may be based on unexamined biases. Failure to become aware of these biases may cause first responders to respond to survivors of crime with disabilities incorrectly or ineffectively, and even place them in danger (Vera Institute of Justice, 2020b).

Implicit bias can be particularly challenging at the critical point when the survivor describes what happened to them. First responders should recognize that disclosures unfold in various ways, and it will not always be clear from the outset exactly what is being reported. This is particularly true for survivors with disabilities that affect their cognition or communication. First responders must keep this in mind and listen carefully to statements made by the survivor as well as statements made by third parties supporting them. It is vital that they not immediately discount what the person is reporting if what they say does not make sense or fit together in a way that seems coherent to the first responder (Vera Institute of Justice, 2020c).

Audiences: Self-Advocates, Family/Friends/Allies, First Responders, Criminal Justice Agencies

Special Populations/Issues: Children With IDD, PwIDD Who Communicate Without Speech

## Adjudication

When assault or abuse is reported, many cases do not lead to conviction or prosecution (Dickman et al., 2006; National Association of Councils on Developmental Disabilities, 2017). In 1994, even when an offender was identified, only 24% of offenders were charged with sexual assault of a PwIDD, and only 8% were convicted. As of 2018, there were no updated numbers on these statistics. However, researchers and other professionals in the field said that while the number of offenders charged had gone up, still only a small minority were convicted (Shapiro, 2018e). The National Association of Councils on Developmental Disabilities (2017) states that while 70% of serious crimes committed against people without disabilities were prosecuted, only about 5% of serious crimes committed against people with disabilities were prosecuted. The first responder interviewed for this project also expressed discouragement about under-prosecution of sexual assault against people in general and PwIDD in particular, citing the complex nature of these cases, prosecutor turnover rates, and the marginalization of some groups of people, including PwIDD. What many do not realize, they said, is that justice is a form of healing for survivors. Depriving survivors of justice was, in a way, a refusal to let them heal.

The significance of this problem may be due in part to the extreme difficulty in prosecuting (let alone winning) sexual assault cases involving PwIDD. Some contributing factors include challenges PwIDD may have describing what happened, some PwIDD not being able to communicate with speech, and some PwIDD having problems remembering precise details—which makes them easy to confuse in a courtroom (Shapiro, 2018e).

Prosecuting sexual assault cases that involve PwIDD can also be complex, particularly when the ability of the survivor to testify is in question. For example, a 2015 case involved a professor who was accused of sexually assaulting a man with IDD who could not communicate with words. The professor stated that she and the man had a consensual relationship and loved each other. The prosecution won the case. But in 2017, the court of appeals overturned the conviction citing that the judge had not allowed the defense testimony that the man could communicate consent to the sexual relationship with a controversial technique called “facilitated communication” (Shapiro, 2018e).

Successful adjudication of sexual assault cases provides a path to healing for survivors. They deserve the opportunity to see justice done for what they experienced, just as they are worthy of the respect and protection afforded to other survivors. This section describes positive changes to the adjudication process including better inclusion and representation of PwIDD in court proceedings. It also explores how prosecution is hindered by systemic biases, problems with evidence, ineffective or inappropriate laws, and incomplete or ineffective representation.

### Opportunities

#### *Self-Advocacy and Inclusion*

PwIDD and their families have begun demanding prosecution of sexual assault cases. For example, the head of a developmental disabilities programs in Pennsylvania indicated that as PwIDD become

more integrated into society, people have begun to know them better. This has led to prosecutors in that state being more willing to take cases to trial. It has also helped to educate judges about how to better handle these cases (Shapiro, 2018e).

Another program has improved prosecution by ensuring self-advocates are included in the adjudication process and by examining family and caregiver influence on the survivor's investment in the court process. When family or caregivers have attitudes toward prosecuting that are opposite of the self-advocate's, legal professionals must become aware of this situation and ensure the self-advocate is making an independent decision about their role in adjudicating the case (Dickman et al., 2006).

Self-advocates interviewed for this project expressed a general fear regarding testifying in court, fear about the outcome and how their testimony could affect it, and fear regarding testifying and the case being dismissed. They emphasized the importance of having support of trusted people as key to alleviating this fear of the adjudication process. One self-advocate discussed their experience in court during custody hearings and stated that what helped them get through the experience and feel comfortable was having many people there who they trusted and who supported them. A potential strategy to address adjudication problems that the first responder interviewed for this project thought would be effective is having specially trained advocates independent of the person's family or guardian for PwIDD going through adjudication.

Audiences: Self-Advocates, Family/Friends/Allies, Criminal Justice Agencies

### *Accessibility Planning and Screening*

Legal professionals should not wait for a person with a disability to initiate access to legal services and programs before thinking about access and communication needs. They should prepare ahead of time to ensure accessibility, effective communication, and true inclusion. Screening of survivors should address any physical and emotional safety concerns they may have. The screening process should not be used to exclude people from services but rather to identify what the survivor might need to participate fully in the process. For example, instead of asking if someone has a disability, a legal professional should ask what accommodations the person needs. Asking about what accommodation a person needs gets the necessary information more quickly and directly than asking a person about their disability (Vera Institute of Justice, 2020b).

The Sexual Assault Victim Empowerment program (SAVE) in South Africa uses an in-depth screening process for clients with IDD who have been sexually assaulted that includes screening in the following areas:

- formal assessment of cognitive and communication needs
- competence to act as a witness (noting that competence is increased with compassionate support of the survivor and appropriate preparation for court)
- ability to give a consistent account of the assault

- assessment of suggestibility (ability to be led by questions) and acquiescence (answering "yes" to all or most questions)
- understanding of the court proceedings
- ability to take the court oath
- how invested the person is in prosecuting the case
- an assessment of the ability of the person to consent to sexual contact (Dickman et al., 2006)

Effective communication that works for the client is also part of ensuring accessibility. Effective communication with PwIDD may include simplifying language, slowing speech, using visual cues, repeating requests as needed, and reviewing for understanding. Legal professionals should check in often to ensure the survivor's needs are being met and to evaluate the accessibility of their current forms of communication (e.g., phone, email, computer, files, and aids). They cannot expect their clients to provide their own accommodations (Vera Institute of Justice, 2020b).

Audiences: Self-Advocates, Family/Friends/Allies, Criminal Justice Agencies

Special Populations/Issues: PwIDD Who Communicate Without Speech, International Issues

### *Preparation of PwIDD for Court Proceedings*

Legal professionals do not always have the tools or knowledge to work effectively with people with disabilities and may not understand how to ensure effective representation. Best practices encourage going beyond minimum responsibilities to facilitate access for people with disabilities more effectively. In one case, for example, a prosecutor took her client to the court where she would testify. While there, she showed the woman where everyone would be sitting and allowed her to sit where she would testify. She also met the judge, who explained the court process (Shapiro, 2018e). A program in South Africa also provides court preparation for the survivor that includes visiting the court, meeting the prosecutor, learning who will be involved in the court process and what each person's role will be, and preparation for cross-examination (Dickman et al., 2006). The self-advocate working on this project affirmed that providing information and walk-throughs of the courtroom could be helpful. They added that role-plays, which are effective in helping PwIDD learn and internalize information, could be very helpful in preparing self-advocates for court.

Audiences: Self-Advocates, Family/Friends/Allies, Criminal Justice Agencies

Special Populations/Issues: International Issues

### *Alternate Methods of Testimony from PwIDD*

Several studies have shown improved positive outcomes of adjudication of sexual assault cases perpetrated against PwIDD by allowing alternate methods of providing testimony. The program in South Africa allows survivors with IDD to provide evidence via closed circuit television, with support

from trained assistants (Dickman et al., 2006). Other methods for facilitating testimony for PwIDD include allowing specially trained service animals for support during the trial and allowing the testimony of PwIDD to be videotaped outside of the trial (Shapiro, 2018e). In Pennsylvania in 2018, legislation passed the House of Representatives that would make testifying easier for PwIDD by outlining steps judges could take to allow testimony to be taken outside of court (Shapiro, 2018h).

Audiences: Self-Advocates, Family/Friends/Allies, Criminal Justice Agencies

Special Issues/Populations: International Issues

### *Better Prosecution Tools*

Prosecutors are beginning to have more and better tools for fighting sexual assault cases involving PwIDD, including better protection for the rights of those who are sexually assaulted, better laws protecting PwIDD, and DNA testing (Shapiro, 2018e). In California, legislation was proposed that would begin a pilot program to give money to prosecutors to investigate cases of sexual assault of PwIDD and take them to court. However, as of 2018, that legislation had stalled (Shapiro, 2018h). A South African program provides guidelines to prosecutors, police, and judges on best practice in adjudicating cases involving PwIDD. This program also saw in increase in the number of cases being prosecuted when they began including expert testimony during the trial (Dickman et al., 2006).

Audiences: Self-Advocates, Family/Friends/Allies, Criminal Justice Agencies

Special Populations/Issues: International Issues

### *Service Provider Advocacy*

Service providers (which may include those providing victim services or those providing general support services to PwIDD) can improve a survivor with IDD’s experience during the adjudication process (Dickman et al., 2006; Vera Institute of Justice, 2020d). Advocacy activities or approaches may include:

- teaching the survivor about the criminal justice agencies so they know what to expect, what questions to raise, and how to advocate for themselves (e.g., providing maps of the courtroom, role-playing, etc.)
- advocating for accommodations the survivor needs to fully participate in the system, ensuring those requests are fulfilled, and checking with the survivor periodically to address changing needs
- connecting with local disability groups to learn how best to provide effective services for the survivor
- working with investigators to spread out interviews over several appointments, if needed
- advocating for the presence of a support person during interviews, if needed
- checking the survivor's eligibility for and facilitating access to their state’s crime victim compensation program

- helping the survivor monitor their case, for example by facilitating regular communication with the prosecutor's office or helping the survivor access the Victim Information and Notification Everyday (VINE)
- ensuring the survivor remains connected to long-term supports for healing (Vera Institute of Justice, 2020d)

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, Criminal Justice Agencies

## Challenges

### *Inability to Substantiate Assault or Abuse*

Substantiating sexual assault or abuse claims is more challenging in cases involving survivors with IDD. This is compounded when the survivor has cognitive and/or communication challenges. For example, the survivor may not be able to communicate using speech at all, may not be able to describe important details, or may not be able to recount events in correct time sequence. Because often the perpetrator is known to the survivor, others around the survivor may attempt to interfere in the investigation. They may pressure the survivor to recant or change their story. In one case, a caregiver with whom the survivor lived called the investigating officer, without the survivor's knowledge, and falsely stated the survivor had recanted (Shapiro, 2018a). Several service coordinators interviewed for this project also discussed how the people that they work with often say what they think others want to hear or what they think they are supposed to say, making it more difficult for them to effectively testify for themselves.

Relevant Statistics:

NPR collected data from state agencies that provide services and protect PwIDD and asked how often allegations of sexual assault were substantiated. These are some of the statistics.

- Texas: less than 1%
- Florida: about 5%
- Ohio: 23%
- Pennsylvania: 34% (Shapiro, 2018b)

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, Criminal Justice Agencies

Special Populations/Issues: PwIDD Who Communicate Without Speech, Congregate Living, Reliance on Perpetrator, Domestic and Intimate Partner Violence

### *Reporting Delays*

The *Reporting* section of this framework details challenges associated with timely reporting of sexual assault and abuse of PwIDD. These delays in reporting for various reasons can make it difficult to seek prosecution. Often, sexual assault and abuse is discovered only by accident—and by the time it is discovered, vital evidence may be gone. For example, a cold case was reopened

concerning a woman with IDD who had been impregnated 13 years before. A DNA match was found for the perpetrator, but the statute of limitations had expired, so the man responsible was not prosecuted (Shapiro, 2018b).

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, Criminal Justice Agencies

Special Populations/Issues: PwIDD Who Communicate Without Speech, Congregate Living

### *Prejudice*

Due to prejudice and bias, people may unwittingly believe and perpetuate myths and negative stereotypes about PwIDD who have been assaulted. Two common myths are that PwIDD cannot understand what sexual assault is and that PwIDD cannot feel emotions. These myths played a significant role in a case involving a 15-year-old girl with autism and other developmental disabilities who was sexually assaulted in her high school bathroom by a special education classmate with similar disabilities. The girl's family sued the school district, but the school district claimed that a sexual assault did not occur, and even if it had, the girl could not have been emotionally injured because she could not have appreciated what happened as a sexual assault. They also claimed she was incapable of remembering the incident. Despite expert testimony that explained the girl could feel emotions and showed signs of trauma from sexual assault, the judge ruled a mistrial. A second trial found in favor of the girl, but she and her family experienced years of adjudication to reach that conclusion (Failure to prevent assault on student with disabilities, 2015).

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, Criminal Justice Agencies

Special Populations/Issues: People with Autism, PwIDD Who Communicate Without Speech

### *Repeat Offenders*

Few people who commit sexual assault against people with disabilities are ever charged or convicted. This means perpetrators who are not prosecuted will not show up on criminal checks used to keep people with disabilities safe, leading to repeat offenses. This is of particular concern when perpetrators are providers of service to PwIDD or direct care workers (Pennsylvania Coalition Against Rape, n.d.). To address this challenge, the state of Massachusetts passed a law creating a registry of abusive caregivers, even if the person's case was not prosecuted (Shapiro, 2018h). However, this practice is not widespread.

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, Criminal Justice Agencies

Special Populations/Issues: Congregate Living, Reliance on Perpetrator

### *Unclear Offenders*

Shapiro (2018b) explains how, for PwIDD who cannot communicate with words, sexual assault is often discovered by accident or goes unsubstantiated. One woman with IDD who could not communicate with words, for example, was found to have gonorrhea. She lived with a family of all

women. Investigators examined men at an outside care facility the woman attended previously, but they could not determine who assaulted her, so no one was punished or stopped from abusing others.

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, Criminal Justice Agencies

Special Populations/Issues: PwIDD Who Communicate Without Speech, Congregate Living

### *Use of Laws Designed for Juvenile Criminal Justice Agencies*

There is debate among service providers about whether PwIDD should be educated and protected by laws in the same manner children are. PwIDD have developed life skills, including ways to communicate, that are different from what a child would have, indicating a need for laws separate from those protecting children (Vera Institute of Justice, 2020c). While PwIDD are sometimes described as having child-like joy and appreciation of life, some professionals point out that they are also adults who want things other adults want, including jobs, community, and relationships (Shapiro, 2018a). Additionally, PwIDD may be sexually active, and they have the ability to consent to sex—which is a significant difference from children (Vera Institute of Justice, 2020c).

Professionals point out that patronizing and infantilizing PwIDD may actually prevent them from learning skills appropriate for their age, including skills that may keep them safe. Nonetheless, in the United States, 32 states use the same laws to protect PwIDD from sexual abuse as they use to protect children (Shapiro, 2018a).

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, Criminal Justice Agencies

### *Incomplete or Ineffective Representation*

Legal professionals do not always have the tools or knowledge to work successfully with people with disabilities and may not understand if and what their responsibilities are to ensure they provide effective representation. Best practices involve going beyond minimum responsibilities to promote access more effectively. This is critical, as incomplete or ineffective representation can lead to serious consequences for the survivor, including:

- limitations in due process
- lack of full participation in a trial
- lack of needed victim compensation
- lack of access to protection order remedies such as custody of children or temporary full-access to the family home (Vera Institute of Justice, 2020b)

Audiences: Self-Advocates, Family/Friends/Allies, Criminal Justice Agencies

## Survivor Support

Supporting a PwIDD who has experienced sexual assault is a vital component to their healing. It is important to keep in mind that the nature of their disability often requires specialized approaches to this support. Those providing services must consider accessibility for the survivor and reflect both the specific and diverse ways trauma affects survivors with IDD. This section describes the general approaches and specific treatments that may be effective in improving recovery outcomes for PwIDD, including adapted therapies, support offerings, and legislative protections.

Survivors with IDD, like anyone, also need a variety of healing supports and strategies to draw from. One self-advocate survivor interviewed for this project discussed their experience with recovery. Supports they found helpful included psychotherapy, meditation, family support, and speaking with their life adjustment team and those in their psychiatric community integration program. Helpful strategies for managing stress included coloring (on paper and in an app), using a stress ball, and talking to their support people.

While these opportunities are supported by researchers and experts in the field, it is unclear the extent to which they are available to survivors with IDD on a day-to-day basis. For example, peer support and support groups are defined as strategies beneficial to the recovery of survivors with IDD. However, we were not able to find any such programs or groups formally available to PwIDD. Similarly, post-assault safety planning is seen as a positive practice. Yet, the self-advocate working on this project did not have access to such a plan after their assault. And based on interviews with self-advocates in congregate housing and service coordinators, policies and procedures around sexual assault and abuse safety are at best inconsistent, at worst absent.

When one also considers pervasive challenges such as the dearth of practitioners formally trained to treat PwIDD and ineffective or even harmful responses to survivors with IDD, it is clear that a significant number of survivors with IDD are likely suffering without support.

## Opportunities

### *Education About Survivors With IDD*

Disability is a complex experience that reflects the interaction between features of a person's body and features of the society in which they live (Vera Institute of Justice, 2020a). A more inclusive way of viewing disability and abuse can be to assume every person with a disability could be a survivor of assault or abuse and that every survivor could have a disability (Vera Institute of Justice, 2020d).

Vera Institute of Justice (2020d) suggests that the only way to know for sure that someone is being traumatized or has experienced trauma is to ask them. Most people with disabilities who have experienced assault or abuse state that although they may have been abused many times in their life, no one ever asked about the possibility of past or current trauma.

There are specific considerations service providers who work specifically with survivors of assault or abuse should be aware of when working with survivors with disabilities, as these may impact the way services are provided. These include:

- overcoming informal practices that may exclude people with disabilities
- being aware of guardianship and the limits of this legal authority
- understanding mandatory reporting and how it might impact confidentiality
- understanding the legal acceptance of service animals
- allowing non-offending personal care attendants to be present (Vera Institute of Justice, 2020d)

Other service providers not working specifically with survivors of assault or abuse should consider some issues that are unique to survivors with disabilities. These include:

- survivors having a say in how their private information is shared
- understanding how mandatory reporting can impact survivors with disabilities, having consistent policies surrounding mandatory reporting, and communicating these policies clearly
- understanding the connection between survivors with disabilities and potential victimization by staff members
- recognizing they may be serving both survivors with disabilities and their offenders—and all resulting safety concerns (Vera Institute of Justice, 2020d)

It is vital that service providers are aware that re-traumatization can occur through certain service provider practices and systems. Some of these practices include the following:

- using any seclusion or restraint
- mislabeling the person’s symptoms as mental or behavioral health issues rather than as traumatic stress reactions
- being overly authoritative when interacting with the person
- assigning any treatment homework that could humiliate the person
- utilizing a confrontational approach
- presenting treatment as conditional based on the service provider’s beliefs
- challenging or discounting reports of assault or abuse
- allowing the abusive behavior of one service user toward another to continue without intervention
- being unaware that the person’s trauma significantly impacts their life (Vera Institute of Justice, 2020d)

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, IDD Agencies, Criminal Justice Agencies

Special Populations/Issues: Congregate Living, Reliance on Perpetrator

### *Accessible Support Services*

Policies of agencies where service providers work specifically with survivors must promote the full participation of people with disabilities. Some examples of policies promoting accessibility include:

- flexibility for where staff can meet and provide programming to survivors
- allowing non-offending personal care attendants to accompany survivors
- tailoring the length of sessions with survivors based on each survivor's needs

Screening that specifically asks about the need for accommodations or about the presence of violence in someone's life should be an ongoing conversation between people seeking or using services and the disability-related or anti-violence organizations providing them (Vera Institute of Justice, 2020d).

All agencies that work with PwIDD should have policies in place that address best practices for communication as well as how survivors will access the program and its services. This policy should be reviewed each year to ensure it is still serving PwIDD optimally (Vera Institute of Justice, 2020b).

Often, disability is not visible, thus it may not be possible to determine who needs accommodations. Best practice is to ask every person if they need any accommodations. Service providers should ask during the first interaction with a survivor and continue to ask at every new step in the process or with every new activity or service in which the survivor will participate (Vera Institute of Justice, 2020d).

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, IDD Agencies, First Responders

### *Intersectional Approaches*

Service providers and other agencies should use intersectional approaches when developing programs that respond to abuse. Solutions must accommodate culture, race, disability, gender, sexual orientation, gender identity, and other important aspects of identity. Service providers and agencies that offer services to survivors of assault or abuse must be able to provide alternative services that are accessible and culturally relevant to all their clients (Cramer & Plummer, 2009).

To protect those whose intersectionality includes disabilities, policymakers and service providers must evaluate and reform mandatory reporting laws, fill research gaps, promote effective prevention efforts, and enhance responses and support to survivors with disabilities (Smith et al., 2017).

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, First Responders, IDD Agencies, Policymakers

Special Populations/Issues: LGBTQ Community, Racially- and Ethnically-Marginalized Communities, People with Autism, PwIDD Who Communicate Without Speech

### *Recognizing and Mitigating Trauma Triggers*

A person who experiences prolonged and repeated exposure to trauma can suffer permanent changes in their brain (Vera Institute of Justice, 2020d). People who have been assaulted or abused can experience trauma trigger, which sets off a memory or flashback. Triggers can be set in motion by different sights, sounds, touches, smells, and tastes. Some examples include seeing someone who resembles the abuser or a trait of that person; hearing sounds associated with anger, pain, or fear; the way someone approaches the person; smells associated with the abuser or the place of abuse; and taste of food associated with the abuse—before, during, or after the incident. Support providers with and without experience with PwIDD must be aware of potential triggers, how to identify when a client might be triggered, and how to safely address the trauma (Vera Institute of Justice, 2020d).

The self-advocate working on this project relayed an experience with trauma trigger when they were at an airport. They told the TSA officer at the security line that they were a trauma survivor. Instead of offering support, the officer "rolled his eyes at me." The self-advocate has had to work hard to recover from that experience.

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers

### *Safety Planning*

Vera Institute of Justice (2020d) explains that when a disclosure of abuse is made to family, friends, allies, or service providers, it is critical to support the person by creating an immediate safety plan while also connecting them to victim service providers who can help create a more in-depth plan. The first responder interviewed for this project suggested specific questions other first responders should ask to better understand what will happen when the patient leaves the hospital:

- Is their residence safe?
- Who will take them there?
- Are they going somewhere where they can rest and heal?
- Does the survivor have important phone numbers readily available to them?
- Does the survivor have access to safe transportation?
- Does the survivor have access to food in the home?
- Does the survivor have connections to needed services?

Vera Institute of Justice further explains that post-report, service providers who have a plan and proper response to survivors can provide referrals, address safety concerns, and respond to disclosures. This gives survivors support and vital resources, both of which lead to healing. They also warn that abusive people can change their control tactics, so the safety plan should be reviewed on a regular basis and updated as needed. Safety plans should address the following:

- accessibility of transportation
- personal care and adaptive equipment needs

- medications
- code words the person could use with trusted others in times of crisis
- items they should take with them when leaving such as important documents, financial resources, medical information, and other supplies and aids

It is also important to remember that safety is a complex concept for some people with disabilities. Safety may be something they have never felt (Vera Institute of Justice, 2020d). The self-advocate working on this project emphasized they are not one size fits all—safety plans should reflect the individual's experiences, needs, and preferences.

The self-advocate also shared that safety planning should acknowledge recovery needs. For example, they did not have a safety plan and had to make decisions about how to keep away from the perpetrator. They became more worried about reaching out to make new friends and were therefore more isolated. They feel survivors should have a plan that guides them to know how not to lose important parts of their life because of what a person did to them.

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, IDD Agencies, First Responders

Special Populations/Issues: Congregate Living, Reliance on Perpetrator, Domestic and Intimate Partner Violence

#### *Family and Caregiver Support*

When working with sexual assault survivors with IDD, it is likely that the therapist will be in contact with family members, caregivers, or other support people who are a part of the survivor's life. Family and caregiver input is essential in learning more about the survivor and any changes noticed in the person because of the trauma. However, it is important to remember that having any type of support person present in the therapy is always the choice of the survivor. It is also common for those close to the survivor to experience vicarious trauma. Attention to their trauma is essential, as their healing can affect the survivor's healing as well (Vera Institute of Justice, 2020d).

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, IDD Agencies

#### *Natural Supports*

Creating relationships with people in the community can lead to building a strong support system. These relationships are called natural supports and can be built through family, significant relationships such as close friends, relationships through shared experiences such as being neighbors or working in the same place, and relationships that are built on economic exchanges such as those with taxi drivers or doctors. There are many ways to develop natural supports, and no two sets of natural supports will ever be alike. Natural support systems may change over time, as the needs and desires of the person being supported change. They can also change in response to experiencing a violent crime and can be an important part of supporting a survivor after they have experienced assault or abuse (Vera Institute of Justice, 2020d).

The self-advocate working on this project felt having a lot of significant connections in the community was important to their recovery. Survivors need people to brainstorm with, to process with. They felt it was a tricky balance between finding ways to be in the community but to be safe in the community. "You have to be out in the world, but you have to be safe out in the world."

Audiences: Self-Advocates, Family/Friends/Allies; Service Providers, IDD Agencies

### *Peer Support*

Peer support is an important method of reaching survivors and is integral to educating and supporting people with disabilities. Peer support can be found through mental health peer support, cross-disability peer support, self-advocacy programs, and disability-specific peer programs (Vera Institute of Justice, 2020d). The first responder interviewed for this project felt there was a significant need for a "network of support" that connected survivors and allowed them to receive support within their comfort zone. The self-advocate working on this project felt that talking to other survivors was helpful in their recovery (although they did not have formal peer support). However, they felt it was also important that survivors be careful about their own wellbeing—to take care not to be triggered in discussion about other survivors' trauma.

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, IDD Agencies

### *Survivor Support Groups*

PwIDD who are survivors of sexual assault or abuse can benefit from survivor support groups. These groups can provide sex education; reduce trauma, depression, and anger; and help improve self-esteem (Peckham et al., 2007). A group of survivors of sexual assault who were also diagnosed with IDD participated in a group where education on sexual abuse was a prerequisite to therapy. The caregivers of the survivors participated in a separate educational support group. After 20 sessions, the survivors were able to reduce levels of both trauma and depression (Peckham et al., 2007).

Self-advocates interviewed for this project discussed the need to talk about their feelings with someone trustworthy who will listen to them. The self-advocates discussed how helpful the internet is for finding and connecting with other survivors.

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, IDD Agencies

### *Psychotherapy*

Despite misconceptions about PwIDD and psychotherapy (see related *Challenge* below), there are many benefits of therapy for trauma survivors with IDD, including:

- relief from the psychological impact of the assault
- recovery from the physiological and psychological changes experienced from the trauma
- reduction in depression, anxiety, phobias, anger, and other common trauma-related symptoms

- lessening or elimination of nightmares, daymares, or re-experiencing of the trauma
- stabilizing mood and other positive changes in behaviors such as toileting, eating, sleeping, and dressing (Vera Institute of Justice, 2020d)

Some types of therapies effective for trauma survivors include:

- cognitive behavioral therapy (CBT)
- eye movement desensitization and reprocessing (EMDR)
- thought field therapy (TFT)
- art, music, and dance therapy
- equine therapy
- journaling therapy
- mind-body therapies, including meditation and yoga
- psychological energy therapies

These therapies can help survivors understand that their responses to trauma are normal and similar to what others have experienced (Vera Institute of Justice, 2020d).

Psychoeducation can be an important part of psychotherapy for PwIDD. Psychoeducation gives information about the therapeutic process to the person receiving therapy and their family or caregiver. Often, the therapist provides information about sexual assault such as a description of perpetrators, why they commit these crimes, and a comprehensive understanding about sexual assault and how and why it is so common in society. Often, survivors may feel that some aspect of who they are caused the assault. In reality, the assault is solely caused by the perpetrator, not the survivor. Psychoeducation can help the survivor understand these dynamics and promote healing (Vera Institute of Justice, 2020d).

Children who have been sexually abused may benefit from specialized therapy, including individual therapy, family therapy, group therapy, trauma-focused cognitive behavioral therapy, and child-centered therapy. For children with autism, it is recommended to work with therapists that have experience with autism, have worked with children with autism, or have already worked with that child before. Therapy should incorporate preferred communication and behavioral supports (Autism Speaks, n.d.).

While discussing recovery for survivors of sexual assault or abuse, service coordinators interviewed for this project mentioned the importance of counseling to help people understand and express their feelings. One service coordinator stated there is often confusion regarding sexual assault experiences. They felt that helping survivors understand and feel more secure in themselves can aid in the healing process. However, service coordinators noted a lack of therapeutic services for PwIDD and felt these services need to be made more available.

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, IDD Agencies

Special Populations/Issues: People with Autism, Children With IDD

### *Legislative Protections*

Survivors can use existing legislation to advocate for their needs post-assault. For example, the Fair Housing Act prohibits discrimination based upon domestic violence situations. Landlords cannot penalize survivors of domestic violence who break their leases to leave a violent situation or for nuisance-related activity, such as police presence. Similarly, the Individuals with Disabilities Education Act (IDEA) provides remedies for students with disabilities who experience inappropriate conduct by professionals and staff at school, including sexual abuse (Vera Institute of Justice, 2020a).

Title III of the ADA prohibits discrimination against people with disabilities in businesses and programs that are open to the public, including most crime victim advocacy agencies. These protections ensure that PwIDD who need support services after experiencing assault are allowed to receive the same services people without disabilities receive and cannot be denied any services based on their disabilities. This law also means PwIDD are not required to pay for any necessary accommodations to receive these services (Vera Institute of Justice, 2020c). Knowing about these legal protections can empower self-advocates and those supporting them, which aids in overcoming trauma and maintaining safe distance from the perpetrator.

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, IDD Agencies, First Responders, Criminal Justice Agencies, Policymakers

Special Populations/Issues: Children With IDD, Transition-Age Youth, Reliance on Perpetrator, Domestic and Intimate Partner Violence

### *Advocacy*

The self-advocate working on this project emphasized that their advocacy around sexual assault has been an important source of healing. By presenting at conferences, working on important projects, and sharing their story with others, they have been able to change negativity to positivity. However, they caution that self-care must be the first priority. They remember the SANE nurse working with them said to go slowly, recover for yourself first, then talk about it to others. It can take years to do that kind of soul searching and healing. Self-advocate survivors interviewed for this project affirmed that self-advocacy helped them in their recovery. Some self-advocates expressed the need to learn how to be a self-advocate, stating that it was not something that came naturally.

They also emphasized that if a survivor does not want to tell their story, that is okay. Even years later it is okay to change your mind about telling your story. It is also important to learn that people may criticize you for telling your story. Building a group of supporters as you speak out more can help with that process.

Audiences: Self-Advocates

## Challenges

### *Punitive Approaches to Sexual Assault*

Often, PwIDD who have been sexually assaulted or abused receive direct or indirect punishment for the behavior that stems from unaddressed trauma. Adverse childhood experiences (ACEs) can have lasting, negative effects on health, well-being, and opportunity. These may take the form of both psychological and physical difficulties (Vera Institute of Justice, 2020d). For example, PwIDD who have been sexually assaulted may act out with aggression or property destruction because of the trauma and flashbacks connected to it.

Many PwIDD have been subjected to behavior modification approaches, in which their preferences have been ignored without their understanding of why this happened (Vera Institute of Justice, 2020d). Service coordinators interviewed for this project affirm that sometimes PwIDD express emotion and service providers categorize it as a behavioral problem. They felt there is a need for services that help PwIDD feel more comfortable expressing how they feel as well as better understanding for service providers of the differences between emotional and behavioral issues. The self-advocate working on this project also expressed worry about people with IDD who have negative behavior possibly related to an unreported sexual assault. They have seen behavior plans used inappropriately in residential and day habilitation settings rather than attention paid to the reasons behind the behavior, and they worry this could happen to survivors of sexual assault.

Sometimes PwIDD are mistakenly put on psychotropic medication because of their behaviors, which complicates their treatment (Shapiro, 2018f). A self-advocate survivor interviewed for this project recounted professionals wanting to "push medication," stating that was not what they wanted or needed in their recovery. It is important during therapy to address all issues that affect trauma, even the smaller issues, to allow for healing from those events and traumas during therapy (Vera Institute of Justice, 2020d).

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, IDD Agencies, First Responders

Special Populations/Issues: Children With IDD, PwIDD Who Communicate Without Speech, Congregate Living

### *Lack of Specialized Therapy*

Some professionals believe PwIDD cannot be treated with therapy. Often, PwIDD are perceived as simple. In reality, PwIDD are complex and can be helped with therapy (Shapiro, 2018f). Accessing therapy to meet the complex needs of PwIDD can be challenging. There are many mental health practitioners who provide post-trauma therapy. However, most do not have education specific to treating PwIDD or experience working with PwIDD. Many therapists have had to create their own training program or rely on related experience such as prior involvement with PwIDD. They have adapted this experience to their delivery of mental health services (Vera Institute of Justice, 2020d).

In Texas, the Texas Center for Disability Studies, as of 2020, notes that when making referrals for trauma therapy (due to limited in-house services), finding therapists who have the training and experience with PwIDD is difficult. They were also not aware of universities providing required educational courses on how to treat trauma survivors with IDD. However, the Center's current project, *The Road to Recovery*, prepares trainers statewide to deliver a 2-day training curriculum to address the needs of children with IDD who have experienced trauma. This project encourages therapists skilled in Trauma-Informed Care to expand their services to PwIDD. A second version of the program designed for adult trauma survivors with IDD is in the piloting stage and should be available soon (Vera Institute of Justice, 2020d).

The self-advocate working on this project described their experience with a therapist from the local rape crisis center at the hospital after they reported their assault. The therapist was helpful in teaching them about what was happening and what would happen next. The self-advocate also received therapy for about a year from the center, which was very helpful to their recovery.

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, IDD Agencies

Special Populations/Issues: Children With IDD

## Special Populations

### *LGBTQ Community*

Many PwIDD are also members of the LGBTQ community. According to Rudacille (2016), a handful of studies have been conducted over the past five years, and more going back to 1996, that show that people with autism are more likely to experience gender dysphoria than people in the general population. Autism and gender dysphoria share some of the same symptoms, which can make it more difficult to detect one or the other. In addition, Holmes et al. (2019) cites a study by Glidden (2016) that indicates a high number of people with autism identify as transgender, non-binary, or agender. They recommend further study to examine gender identity and sexual orientation in this group and to identify specific support needs and strategies.

While little research specific to this subgroup was identified, inferences can be made based on intersectionality research (describing how multiple aspects of identity define a person with respect to an issue), research on PwIDD, and research on the LGBTQ community with respect to sexual assault and abuse. Overall, PwIDD who are members of the LGBTQ community are at higher risk for sexual assault based on the multiple risk factors at play in their identities. In addition, the biases against PwIDD that permeate nearly every aspect of the sexual assault and abuse continuum are compounded based by gender identity and/or sexuality (Vera Institute of Justice, 2020b). Service providers and other agencies interacting at various stages are encouraged to use intersectional approaches when developing programs that respond to abuse, which must accommodate sexual orientation and gender identity (Cramer & Plummer, 2009).

It is also likely that PwIDD who are members of the LGBTQ community face special or more acute challenges at many specific points on the sexual assault prevention and response continuum.

#### Prevention

- Targeted efforts that identify people in the community who are most at risk of sexual assault work best when they examine multiple aspects of identity. For example, a collaborative program between the Hawaii Developmental Disabilities Council and Department of Health identified aspects of identity that placed individuals at greater risk. They then used these profiles to target awareness-building and prevention efforts (National Association of Councils on Developmental Disabilities, 2017).
- Holmes et al. (2019) indicate that sexuality and relationship education is important regardless of the sexuality of the individual. For example, even people who are asexual often are interested in relationships, despite experiencing a lack of sexual attraction, so teaching about healthy relationships is important. Finally, whether people decide to engage in sexual relationships or not, learning about sexuality and relationships helps them effectively interact with others and increases self-determination and self-advocacy.

Reporting

- People in this population may not report an assault to avoid being outed publicly if they have not yet revealed this aspect of their identity (Cramer & Plummer, 2009).
- Race and ethnicity also play a role in this, as BIPOC who are lesbians may not report abuse for fear of stigmatization and retaliation by law enforcement due to sexism, racism, and homophobia (Cramer & Plummer, 2009).

Relevant Statistics:

According to Rudacille (2016):

- Eight to 10% of adolescents and children around the world who attend appointments at gender clinics meet diagnostic criteria for autism.
- Around 20% are shown to have autistic traits.
- Although autism appears more often in the male population, recent research has shown that gender dysphoria is experienced by the same amount of people assigned male and assigned female at birth among those with autism.

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, First Responders

Related Framework Topics:

- Awareness-Building Campaigns
- Intersectional Biases
- Effective and Comprehensive Sexuality and Relationship Education
- Barriers to Effective Sexuality Education
- Autonomy and Choice for Survivors
- Stigma
- Law Enforcement and Agency Bias
- Understanding Barriers to Reporting
- Person-Centered First Response
- Intersectional Approaches

### *Racially- and Ethnically-Marginalized Communities*

PwIDD may also experience the sexual assault prevention and response continuum differently as members of racially- and ethnically-marginalized communities. In general, bias based on actual or perceived disability is compounded by bias based on other factors such as race, ethnicity, and immigration status (Vera Institute of Justice, 2020b). Research emphasizes that service providers and other agencies should use intersectional approaches when developing programs that respond to assault and abuse. Solutions must accommodate culture and race as well as disability. In addition, agencies that offer services to survivors of assault or abuse must be able to provide alternative services that are accessible and culturally relevant to all their clients (Cramer & Plummer, 2009).

It is important to note when addressing challenges based on race and ethnicity to also consider other integral aspects of this identity. For example, one study cautions that there are limitations on analyzing African American women's experience with violence on race or gender alone. The definition of violence must acknowledge the historical context of hierarchical power relations of race, gender, class, nationality, and heterosexism within the United States (Cramer & Plummer, 2009).

People from racially- and ethnically-marginalized communities also experience specific barriers and thus have unique needs at different points on the sexual assault prevention and response continuum.

Prevention

- Regarding sexuality education, one study found that non-white parents taught fewer topics to their daughters than did white parents (Holmes et al., 2019).

Reporting

- Women of color in domestic violence situations may be conflicted by wanting the abuse to end and wanting to prevent a Black man (who is more likely to experience negative treatment and outcomes) from entering the judicial system. Black women's fear of involvement with the criminal justice agencies and social services may also influence them to turn to less formal help in the form of friends, family, and church (Cramer & Plummer, 2009).
- People of color with disabilities who are survivors of abuse have also voiced their fears of differential and prejudicial treatment by law enforcement officials, and this can inhibit reporting of assault (Cramer & Plummer, 2009).
- Stigma about sexual assault can hinder reporting as some cultures promote the belief that family matters should not be made public and informing outsiders would bring embarrassment to the family and their culture (Cramer & Plummer, 2009).
- Immigrants and refugees have unique struggles. A person who is in the country illegally may fear deportation or criminal penalties if they report abuse (Cramer & Plummer, 2009).

Relevant Statistics:

- From 2009 to 2010, people with disabilities from racial and ethnic groups experienced twice the rate of violent victimization than people without disabilities, and multiracial people had the highest rates (Smith et al., 2017).

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, First Responders, Criminal Justice Agencies, Policymakers

Related Framework Topics:

- Awareness-Building Campaigns
- Intersectional Biases
- Barriers to Effective Sexuality Education
- Autonomy and Choice for Survivors
- Stigma
- Mistrust and Fear of Law Enforcement
- Fear of Negative Consequences
- Law Enforcement and Agency Bias
- Understanding Barriers to Reporting
- Person-Centered First Response
- Intersectional Approaches

### *People With Autism*

Some research specifically addressed PwIDD who have a diagnosis of autism. Typically, these sources emphasized aspects of the disability that either inhibited effective practice or indicated specialized approaches across the sexual assault prevention and response continuum.

#### Awareness

- Children with autism who have been abused may have an increase in the intensity and frequency of stimming behaviors, self-injurious behaviors, and repetitive behaviors or may develop new behaviors that were not previously present (Autism Speaks, n.d.).

#### Prevention

- Holmes et al (2019) found that parents of children with autism generally have a high degree of concern about the possibility of sexual assault for their children. But surprisingly, they had not instructed their children on how to report sexual assault or abuse or about pressure or coercion by peers.
- The study also found some characteristics of girls with autism that may make teaching about sexuality challenging for parents. These include more intensive or specialized instructional strategies (and the preparation and planning needed to implement these strategies), greater diversity in terms of gender identity and sexual orientation, and the challenge of understanding the developmental needs of girls who may be less likely to express interest in sexuality and relationships than typically developing peers.

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers

Related Framework Topics:

- Type or Severity of Disability
- Failure to Recognize Signs of Abuse
- Barriers to Effective Sexuality Education
- Prejudice
- Intersectional Approaches

- Psychotherapy

### *Children With IDD*

Children with disabilities are nearly three times more likely than those without disabilities to be sexually abused, and the likelihood is even higher (almost five times) for children with intellectual or mental health disabilities (Smith et al., 2017; United Nations Population Fund, 2018). United Nations Population Fund (2018) described an African study that found nearly every young person interviewed had experienced sexual violence, and most had experienced it more than once. Additionally, United Nations Population Fund described an Australian study that found as many as 62% of women with disabilities under the age of 50 had experienced violence since the age of 15, and women with disabilities had experienced sexual violence at three times the rate of those without disabilities. Finally, they indicated that children with IDD are five times more likely to be subjected to abuse and far more likely to be bullied.

#### Awareness

Children and youth with IDD may demonstrate signs of sexual assault and abuse that may be different from those found in adults. These may include:

- nightmares or other sleep problems that are different from typical sleep patterns
- inability to focus
- changes in eating habits or refusing to eat
- trouble swallowing or an unusual fear of objects near the mouth
- unusual changes in mood
- new fear of specific places or people
- refusal to discuss events with others
- expression of sexual actions or images through varying media, such as drawings
- gifts, such as money or toys, that are out of the ordinary
- negative view of their body, especially the genital area (Vanover, 2016)

#### Risk Factors

- Children with IDD are also often treated differently from their neurotypical peers, and this treatment can negatively impact their risk for sexual assault and abuse. For example, parents may avoid discussing sexuality with their children due to fear about the possibility of sexual assault and abuse. Unfortunately, this lack of information about sexuality and appropriate relationships may put their children more at risk (Shapiro, 2018d).

#### First Response

- Vera Institute of Justice (2020c) describes how giving attention to the special needs of children with disabilities can improve outcomes when gathering evidence. For example, children with disabilities may need multiple, longer interviews and may require more breaks and other adjustments to combat fatigue.

- Interviews should also take place at a neutral, non-isolated place such as a police station or family justice center.
- Interviewers should engage in narrative practice—asking the child about a neutral or positive event that prepares them for the actual interview. They should also be prepared to repeat what they say; limit distractions; ensure privacy for pre-interview questions; adopt a patient, flexible, and supportive attitude; and provide help with forms or understanding written instructions without over assisting or patronizing the child.
- Interview tools helpful for children include allowing the child to draw and using maps and anatomically detailed body drawings. These tools may help the interviewer gain more details, ground the child to specific events, help them demonstrate an action or position, organize the child's narrative, and alleviate anxiety (Vera Institute of Justice, 2020c).

Survivor Support

- Research also revealed some specific remedies and supports for children with disabilities experiencing sexual assault and abuse. For example, the Individuals with Disabilities Education Act (IDEA) can be used to protect students from inappropriate staff conduct at public schools, including sexual abuse (Vera Institute of Justice, 2020a).
- Children with autism who have been sexually abused may also benefit from specialized therapy, such as individual therapy, family therapy, group therapy, trauma-focused cognitive behavioral therapy, and child-centered therapy. Therapists should have prior experience with children with autism and should incorporate preferred communication and behavioral supports (Autism Speaks, n.d.).
- In Texas, the Texas Center for Disability Studies implements *The Road to Recovery*, a program that prepares trainers statewide to deliver a 2-day curriculum to address the needs of children with IDD who have experienced trauma (Vera Institute of Justice, 2020d).

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, First Responders, Policymakers

Related Framework Topics:

- Learned Compliance
- Anti-Bias Activities
- Failure to Recognize Signs of Abuse
- Post-Assault Sexuality and Relationship Education
- Autonomy and Choice for Survivors
- Stigma
- Effective Interviews
- Implicit Bias
- Psychotherapy
- Legislative Protections
- Punitive Approaches to Sexual Assault

- Lack of Specialized Therapy

### *Transition-Aged Youth*

There a is correlation between a person's social and sexual development, and transition age (14-22) is a critical time in a PwIDD's development of appropriate sexuality and relationship skills. Yet, there are significant deficits in the education and support transition-aged youth receive in relation to sexuality and relationships. McDaniels & Fleming (2018) note that as youth age, they begin to get most of their understanding of sexuality from peers—a source of natural learning from which PwIDD are often excluded. The inability to access this knowledge can lead to lifelong challenges, including the inability to maintain social relationships and to navigate appropriate workplace relationships.

At the same time, parents may fail to provide needed education. They may believe their child is not interested due to perceived lack of interest or fear they are ill-equipped to provide this education (Holmes et al., 2019). Parents of PwIDD may also be reluctant to talk with their children about sex because they fear it will lead them to being sexually active and open them up to the potential of sexual assault (Shapiro, 2018d). The information vacuum left by the lack of education provided by parents and peers can be dangerous. PwIDD may turn to other sources such as social media and the internet, which can result in inaccurate information and lead to personal safety issues (McDaniels & Fleming, 2018).

Furthermore, sexuality education often leaves out information critical for youths with IDD, including information about healthy relationships (Holmes et al., 2019); bullying, safety with strangers, texting and sexting, and social media and internet safety (Hughes et al., 2020). In addition, sexuality education for transition-age youth is often too simplistic or uses constructs that do not fully prepare them to recognize danger (Shapiro, 2018d).

#### Prevention

- Formal sexuality and relationship education is an important part of sexual assault prevention for PwIDD that can improve youths' understanding of healthy relationships, awareness of abuse, and safety planning skills (Hughes et al., 2020; Shapiro 2018d).
- A key opportunity to provide this important education is to incorporate sexuality and relationship education as an integral part of transition planning. Rehabilitation counselors who work with secondary school staff may be uniquely positioned to coordinate sexuality and relationship education for the youth they serve and to ensure that it is included as an important component of students' IEPs (McDaniels & Fleming, 2018).

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers

Related Framework Topics:

- Post-Assault Sexuality and Relationship Education
- Barriers to Effective Sexuality Education

### *PwIDD Who Communicate Without Speech*

For PwIDD who communicate mostly or completely without speech, sexual assault prevention and response holds additional challenges and requires special solutions. In general, PwIDD who communicate without speech are more vulnerable to sexual assault. This is compounded by the fact that PwIDD are often taught to be compliant (Pennsylvania Coalition Against Rape, n.d.; Shapiro, 2018a), which may make them easy targets to perpetrators as well as making it more difficult to recognized assault or abuse (National Association of Councils on Developmental Disabilities, 2017; Smith et al., 2017). Specific issues across the sexual assault prevention and response continuum are complicated for people who communicate without speech. The following information highlights some of these issues.

#### Awareness

- People who communicate without speech must rely on those around them to notice and investigate behavioral clues of their assaults (National Adult Protective Services Association, n.d.; Vanover, 2016).

#### Reporting

- Delays in reporting sexual assault and abuse of people who communicate without speech often occur because the sexual assault or abuse is discovered by accident. By the time the assault or abuse is discovered, critical evidence may have been lost or statutes of limitations may have run out (Shapiro, 2018b).

#### First Response

- Evidence of sexual assault or abuse gathered at first response is critical to the eventual success of adjudication. This can be challenging when the survivor has significant communication challenges or communicates without speech. Communications personnel and other first responders should be trained to recognize the existence of communication challenges, and to respond appropriately to ensure that key details of the assault or abuse are properly discerned (Vera Institute of Justice, 2020b).

#### Adjudication

- It is more difficult to substantiate allegations of abuse because the survivor may not be able to communicate using speech, may not be able to describe important details, may not be able to recount events in correct time sequence, or may be influenced or inaccurately spoken for by another person. (Shapiro, 2018e).
- Many PwIDD are not able to give consent to sexual relationships because of cognitive and/or communication challenges. Sexual relationships in these situations could be against the law (Pennsylvania Coalition Against Rape, n.d.). However, in some cases alleged perpetrators have successfully argued that the survivor was able to consent without speech (Shapiro, 2018e).

#### Survivor Support

- PwIDD who communicate without speech who have experienced sexual assault or abuse have few options for assessment and treatment of their trauma (Miller, 2021).
- A 2013 study reported no effective therapeutic technique to treat trauma in PwIDD who communicate without speech (Rowsell et al., 2013).
- More recent research indicates some success in using EMDR therapy to treat trauma that occurs in PwIDD who communicate without speech (McNally et al., 2021; Mevissen et al., 2012; Mevissen et al., 2016).

Audiences: Self-Advocates, Families/Friends/Allies, Service Providers, First Responders, Criminal Justice Agencies

Related Framework Topics:

- Type or Severity of Disability
- Speech and Communication Difficulties
- Anti-Bias Activities
- Failure to Recognize Signs of Abuse
- Law Enforcement and Agency Bias
- Person-Centered First Response
- Effective Interviews
- Implicit Bias
- Accessibility Planning and Screening
- Inability to Substantiate Assault or Abuse
- Reporting Delays
- Prejudice
- Unclear Offenders
- Intersectional Approaches
- Punitive Approaches to Sexual Assault

# Special Issues

### *Congregate Living*

Rates of sexual assault and abuse for PwIDD are likely much worse for those in congregate living situations such as group homes or state institutions (Shapiro, 2018a). In addition, worldwide and in the United States, women living in institutions have historically been subjected to forced abortions, forced sterilizations, exposure to STIs, and sexual violence (Shapiro, 2018d; United Nations Population Fund, 2018). There are a number of factors that contribute to the increased risk of sexual violence for those in congregate living. For example, staff turnover contributes significantly (Pennsylvania Coalition Against Rape, n.d.). This issue was emphasized by service coordinators interviewed for this project, who also indicated staff underpayment and resident overpopulation as contributing factors. They feel this has become an even larger issue in the wake of COVID-19.

Sometimes, the stigma of others in the residence knowing about a person's sexual assault or abuse keeps them from reporting, as described by self-advocates interviewed for this project. Self-advocates also described fear of retaliation by staff and fear of losing their placements as powerful silencing factors.

However, congregate housing institutions' policies and procedures may also inhibit reporting of sexual assault and abuse. For example, self-advocates interviewed for this project reported varying levels of information and support provided despite believing it would be helpful to them. Some individuals living in group homes had information posted in common areas, while others had no information on how to recognize and report sexual assault and abuse.

Institutional investigatory procedures may also delay reporting to law enforcement. Typically, an internal investigation is done first. When the alleged offender is a provider of needed services, congregate staff often wait until a replacement to perform those services is in place before reporting the crime to law enforcement. These delays can result in the offender not being held accountable and even remaining in the residence. In this case, the survivor may remain at risk, and others in the home may also be at risk (Vera Institute of Justice, 2020c). This is particularly disturbing when abuse in congregate settings is ongoing and systemic, in some cases continuing for many years (Shapiro, 2018b).

Relevant Statistics:

- The National Association of Councils on Developmental Disabilities (2017) reports that most incidents of abuse and neglect of PwIDD in congregate care go unreported and estimates that unreported abuse may be as high as 85%.

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, First Responders, Criminal Justice Agencies, Policymakers

Related Framework Topics:

- Learned Compliance
- Lack of Understanding of Boundaries
- Known Perpetrators and Grooming
- Congregate Living
- Failure to Recognize Signs of Abuse
- Not Knowing How to Report
- State and National Actions to Support Prevention of Sexual Assault
- Autonomy and Choice for Survivors
- Not Knowing How to Report
- Stigma
- Fear of Negative Consequences
- Institutional Silence

- Understanding Barriers to Reporting
- Trauma-Informed Care
- Inability to Substantiate Assault or Abuse
- Reporting Delays
- Repeat Offender
- Unclear Offender
- Education About Survivors With IDD
- Safety Planning
- Punitive Approaches to sexual Assault

### *Reliance on Perpetrator*

As described above, almost all abuse committed against people with disabilities is done by someone the individual knows (National Association of Councils on Developmental Disabilities, 2017). PwIDD are most often sexually assaulted by other people with IDD, service providers, relatives, or friends (Shapiro, 2018a). Sometimes a person entrusted to care for the PwIDD can be the abuser, such as a caregiver or someone who drives the PwIDD to appointments or work (Shapiro, 2018g).

Abusers can also be family members, which complicates nearly every aspect of the assault or abuse and its consequences. A self-advocate survivor interviewed for this project indicated that their abuse began with their father, who molested them from a young age and taught them that sex is love. They internalized that message and described how it was exploited by others and led to subsequent abuse years later in life.

When the abuser is known to the survivor, assault and abuse often goes unreported. For example, if the survivor relies on the abuser for daily living assistance, they may not report because they fear losing their independence (Smith et al., 2017). Often, only a powerful motivation can compel the survivor to report. For example, a man abused by a relative did not report until his sister and her children moved into the same house as the relative. Fearing they would be victimized as he had been, he reported his abuse to the police (Shapiro, 2018f).

Abuse may also not be reported when the perpetrator convinces the survivor they have a sexual or romantic relationship. For example, they may say they are a boyfriend or girlfriend to try to coax the person into having sex (Shapiro, 2018f). PwIDD who have been sexually assaulted in this way report feeling dirty and blaming themselves after the assault, while having been treated with kindness by the perpetrator prior to the assault (Shapiro, 2018g).

When a survivor does report sexual assault and they are reliant on the perpetrator, response staff must take special steps to ensure the survivor’s safety and well-being. For example, when first responders conduct an initial interview, they should ensure the survivor has options for alternative living situations, if the current situation is not safe. They should also ensure that an alternate caregiver is available if the current caregiver is arrested (Vera Institute of Justice, 2020c).

It is also important during first response, adjudication, and survivor support to address avoidance of the perpetrator. Few people who commit sexual assault against people with disabilities are ever charged or convicted. This means perpetrators may return to the communities in which they assaulted or abused the survivor. They will not show up on criminal checks used to keep people with disabilities safe, leading to repeat offenses. This is of particular concern when perpetrators are providers of service or direct care workers for PwIDD (Pennsylvania Coalition Against Rape, n.d.). The self-advocate working on this project shared that post-assault safety planning should also address how to avoid the perpetrator if they are not arrested or are released. They had to take on the stress of this responsibility themselves. As a result, they became more isolated, which in turn made them less safe.

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, First Responders, Criminal Justice Agencies, Policymakers

Related Framework Topics:

- Lack of Understanding of Boundaries
- Desire for Friendship or Romantic Relationships
- Known Perpetrators and Grooming
- State and National Actions to Support Prevention of Sexual Assault
- Stigma
- Fear of Negative Consequences
- Understanding Barriers to Reporting
- Person-Centered First Response
- Ready Support and Service Referrals
- Inability to Substantiate Assault or Abuse
- Repeat Offenders
- Education About Survivors With IDD
- Safety Planning
- Legislative Protections

### *Domestic and Intimate Partner Violence*

Domestic or intimate partner violence adds another dimension to the challenges and issues described above. For example, PwIDD may rely on their abusive intimate partners to help with daily living activities, such as toileting, bathing, and eating, and thus may choose not to report abuse (Cramer & Plummer, 2009). This makes it especially important for others in the PwIDD's life to recognize signs of abuse. Some assessments designed to identify interpersonal abuse (which may or may not include domestic or intimate partner violence) such as the Interpersonal Violence Interview (IVI) specifically explore these dimensions including exploitation; sexual, physical, emotional, and financial abuse; and neglect (Atkinson & Ward, 2012).

When a person does report abuse but chooses to remain with the abuser, a detailed safety plan should be developed. Vera Institute of Justice (2020d) emphasizes that these plans must be reviewed on a regular basis and updated as needed to address changing tactics of abusers. They also explain that safety plans should address the survivor's daily living needs, including:

- accessibility of transportation
- personal care and adaptive equipment needs
- medications
- code words the person could use with trusted others in times of crisis
- items they should take with them when leaving such as important documents, financial resources, medical information, and other supplies and aids

Survivors should also know about existing legislation that can protect them post-assault. For example, the Fair Housing Act prohibits discrimination based on domestic violence. Landlords cannot penalize survivors of domestic violence who break their leases or for nuisance-related activity due to domestic violence consequences, such as police presence (Vera Institute of Justice, 2020a). Knowing about these legal protections can empower self-advocates and those supporting them, which aids in overcoming trauma and provides protection against being forced to stay in housing with the perpetrator.

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, First Responders, Criminal Justice Agencies, Policymakers

Related Framework Topics:

- Assessment and Intake Tools for PwIDD
- Intersectional Biases
- Autonomy and Choice for Survivors
- Fear of Negative Consequences
- Law Enforcement and Agency Bias
- Ready Support and Service Referrals
- Inability to Substantiate Assault or Abuse
- Safety Planning
- Legislative Protections

### *Relationships and Relationship Boundaries*

Relationship boundaries are nuanced and change over time. When PwIDD are deliberately or inadvertently deprived of information about boundaries, they are put at risk. For example, they may experience sexual assault but fail to report it because they do not know what it is or that it is against the law (Pennsylvania Coalition Against Rape, n.d.). A self-advocate survivor interviewed for this project said they allowed a person to touch them on their private parts because they did not realize

that this was inappropriate. Abusers may also exploit this lack of understanding by convincing PwIDD that they are romantic partners, and thus it is okay to have sex (Shapiro, 2018f).

This lack of understanding of relationship boundaries is complicated by learned compliance. PwIDD are taught to defer to and obey others in their lives, particularly parents and caregivers. This opens them up to the possibility of being sexually assaulted. It may also give the false perception that people with IDD are weak and easy targets for assault (Shapiro, 2018g).

Confusion about boundaries was reflected in the interviews conducted with self-advocates for this project. Many reported that they understand relationship boundaries. Although some expressed confusion based on context. For example, one self-advocate stated that they sometimes get mixed signals related to coworker, friend, and romantic boundaries. While self-advocates in congregate housing felt comfortable that they understood boundaries with other residents, they also expressed uncertainty about boundaries with service providers who may come into their home. In fact, throughout one listening session a participant continually pressed another for personal information, though they had never met. This resulted in project staff conducting a brief training for the participant's self-advocacy chapter after the session. However, several weeks later it was reported that the participant again was pushing personal boundaries with a different self-advocate.

For some PwIDD, their sexual assault is the only sexual experience they have had, and that may confuse their understanding of the boundaries between appropriate and harmful sexuality (Shapiro, 2018d). This can also be a barrier for survivors who want romantic relationships but have confusion about what is healthy (Shapiro, 2018c). In this instance, post-assault sexuality and relationship education can be helpful (Shapiro, 2018d).

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers

Related Framework Topics:

- Learned Compliance
- Lack of Understanding of Boundaries
- Desire for Friendship or Romantic Relationships
- Known Perpetrators and Grooming
- Failure to Recognize Signs of Abuse
- Effective and Comprehensive Sexuality and Relationship Education
- Post-Assault Sexuality and Relationship Education
- Barriers to Effective Sexuality Education
- Fear of Negative Consequences

### *International Issues*

In the course of researching sexual assault prevention and response, we found several sources that describe this epidemic in other countries. While some aspects differ due in part to different criminal justice agencies and cultural attitudes, we felt inclusion of these issues, strategies, and programs

could only add to the richness of our understanding. These sources are included at point of use in the core framework and summarized here.

The United Nations Population Fund (2018) describes the extent and type of abuse perpetrated against PwIDD worldwide. Females with disabilities face up to ten times more gender-based violence than those without disabilities, and PwIDD are particularly vulnerable to sexual violence. In addition, girls with disabilities are at increased risk of being trafficked for sexual labor. In many places, young people with disabilities are seen as undesirable and are even trafficked by their own families. Girls and young women with disabilities are at greater risk of sexual violence when not in school because neighbors and family members who know they are alone can use the opportunity to sexually assault them with little risk of being caught or punished. And young women living in institutions frequently have their rights violated regarding what happens to their bodies, including being subjected to forced abortions, forced sterilizations, exposure to STIs, and sexual violence.

This violence is sometimes based on perpetuating myths. For example, a common myth in many countries outside the United States is that an STI can be cured by having sex with a virgin. Young women with disabilities have a higher risk of rape by infected people because they are often thought to be asexual and considered to be a virgin. In 2004, a survey on HIV/AIDS and disability found that virgin rapes of people with disabilities occurred in 14 of 21 countries that were surveyed (United Nations Population Fund, 2018).

One international program designed to improve adjudication outcomes of sexual assault cases involving survivors with IDD may offer promising practices that could be used in the United States. According to Dickman et al. (2006), the Sexual Assault Victim Empowerment program (SAVE) in South Africa uses an in-depth screening process for clients with IDD who have been sexually assaulted that enables them to evaluate needs in the following areas:

- formal assessment of cognitive/communication needs
- competence to act as a witness (noting that competence is increased with compassionate support of the survivor and appropriate preparation for court)
- ability to give a consistent account of the assault
- assessment of suggestibility (ability to be led by questions) and acquiescence (answering "yes" to all or most questions)
- understanding of the court proceedings
- ability to take the court oath
- how invested the person is in prosecuting the case
- an assessment of the ability of the person to consent to sexual contact

Supports and strategies are used to improve the likelihood of successful prosecution based on the evaluation of these domains. The program prepares survivors by enabling them to visit the court, meet the prosecutor, learn who will be involved in the court process and what each person's role will be, and prepare for cross-examination. It also allows survivors with IDD to provide evidence via

closed circuit television, with support from trained assistants. Finally, it provides guidelines to prosecutors, police, and judges on best practice in adjudicating cases involving PwIDD. This program also began allowing expert testimony at trial, which resulted in an increase in the number of cases being prosecuted.

Audiences: Self-Advocates, Family/Friends/Allies, Service Providers, Policymakers

Related Framework Topics:

- Known Perpetrators and Grooming
- Congregate Living
- Anti-Bias Activities
- Failure to Recognize Signs of Abuse
- Accessibility Planning and Screening
- Preparation of PwIDD for Court Proceedings
- Alternate Methods of Testimony from PwIDD
- Better Prosecution Tools

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